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First Session  
Thirty-ninth Parliament, 2006

Première session de la  
trente-neuvième législature, 2006

## SENATE OF CANADA

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## SÉNAT DU CANADA

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*Proceedings of the Standing  
Senate Committee on*

*Délibérations du Comité  
sénatorial permanent des*

# Social Affairs, Science and Technology

# Affaires sociales, des sciences et de la technologie

*Chair:*  
The Honourable MICHAEL KIRBY

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*Président:*  
L'honorable MICHAEL KIRBY

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Tuesday, April 25, 2006

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Le mardi 25 avril 2006

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**Issue No. 1**  
Organization meeting

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**Fascicule n° 1**  
Réunion d'organisation

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INCLUDING:  
THE FIRST REPORT OF THE COMMITTEE  
(Expenses incurred during the First Session  
of the Thirty-ninth Parliament)

Y COMPRIS:  
LE PREMIER RAPPORT DU COMITÉ  
(Dépenses encourues au cours de la première session  
de la trente-neuvième législature)



THE STANDING SENATE COMMITTEE  
ON SOCIAL AFFAIRS, SCIENCE  
AND TECHNOLOGY

The Honourable Michael Kirby, *Chair*

The Honourable Wilbert J. Keon, *Deputy Chair*  
and

The Honourable Senators:

Callbeck	Forrestall
Champagne, P.C.	* Hays
Cochrane	(or Fraser)
Cook	* LeBreton, P.C.
Cordy	(or Comeau)
Eggleton, P.C.	Pépin
Fairbairn, P.C.	Trenholme Counsell

\*Ex officio members

(Quorum 4)

LE COMITÉ SÉNATORIAL PERMANENT  
DES AFFAIRES SOCIALES, DES SCIENCES  
ET DE LA TECHNOLOGIE

*Président:* L'honorable Michael Kirby

*Vice-président:* L'honorable Wilbert J. Keon  
et

Les honorables sénateurs:

Callbeck	Forrestall
Champagne, C.P.	* Hays
Cochrane	(ou Fraser)
Cook	* LeBreton, C.P.
Cordy	(ou Comeau)
Eggleton, C.P.	Pépin
Fairbairn, C.P.	Trenholme Counsell

\*Membres d'office

(Quorum 4)

**MINUTES OF PROCEEDINGS**

OTTAWA, Thursday, April 25, 2006

(1)

[English]

The Standing Senate Committee on Social Affairs, Science and Technology met at 8:04 a.m. this day, in room 705, Victoria Building, for the purpose of holding its organization meeting, pursuant to rule 88.

*Members of the committee present:* The Honourable Senators Callbeck, Champagne P.C., Cochrane, Cook, Cordy, Eggleton, P.C., Fairbairn, P.C., Forrestall, Keon, Kirby, Pépin and Trenholme Counsell (12).

*In attendance:* From the Library of Parliament Research Branch: Howard Chodos and Tim Riordan Raaflaub, Research Analysts, Political and Social Affairs Division.

*Also in attendance:* The official reporters of the Senate.

The committee proceeded to organize, pursuant to rule 88.

The Clerk of the Committee presided over the election of the chair.

It was moved by the Honourable Senator Cochrane that the Honourable Senator Kirby be chair of this committee.

The question being put on the motion, it was adopted.

The Honourable Senator Kirby took the chair.

It was moved by the Honourable Senator Kirby that the Honourable Senator Keon be deputy chair of this committee.

The question being put on the motion, it was adopted.

It was moved by the Honourable Senator Fairbairn that the Subcommittee on Agenda and Procedure be composed of the chair, the deputy chair and the Honourable Senator Pépin; and

That the subcommittee be empowered to make decisions on behalf of the committee with respect to its agenda, to invite witnesses and schedule hearings.

The question being put on the motion, it was adopted.

It was agreed that the committee print its proceedings; and

That the chair be authorized to set this number to meet demand.

It was agreed that, pursuant to rule 89, the chair be authorized to hold meetings, to receive and authorize the printing of the evidence when a quorum is not present, provided that a member of the committee of the government and the opposition be present.

It was agreed that the committee adopt the draft first report prepared in accordance with rule 104 and that the chair table the report at the next sitting of the Senate.

**PROCÈS-VERBAL**

OTTAWA, le mardi 25 avril 2006

(1)

[Traduction]

Le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie tient aujourd'hui, à 8 h 4, dans la salle 705 de l'édifice Victoria, sa séance d'organisation, conformément à l'article 88 du Règlement.

*Membres du comité présents:* Les honorables sénateurs Callbeck, Champagne C.P., Cochrane, Cook, Cordy, Eggleton, C.P., Fairbairn, C.P., Forrestall, Keon, Kirby, Pépin et Trenholme Counsell (12).

*Également présents:* Howard Chodos et Tim Riordan Raaflaub, attachés de recherche, Division des affaires politiques et sociales, Direction de la recherche de la Bibliothèque du Parlement.

*Aussi présents:* Les sténographes officiels du Sénat.

Conformément à l'article 88 du *Règlement du Sénat*, le comité procède à l'organisation de ses travaux.

La greffière du comité préside à l'élection du président.

L'honorable sénateur Cochrane propose que l'honorable sénateur Kirby assume la présidence du comité.

La question, mise aux voix, est adoptée.

L'honorable sénateur Kirby prend place au fauteuil.

L'honorable sénateur Kirby propose que l'honorable sénateur Keon soit vice-président du comité.

La question, mise aux voix, est adoptée.

L'honorable sénateur Fairbairn propose que le Sous-comité du programme et de la procédure soit composé du président, du vice-président et de l'honorable sénateur Pépin; et

Que le le sous-comité soit autorisé à prendre des décisions au nom du comité relativement au programme, à inviter les témoins et à établir l'horaire des audiences.

La question, mise aux voix, est adoptée.

Il est convenu que le comité fasse imprimer ses délibérations; et

Que le président soit autorisé à ajuster cette quantité en fonction des besoins.

Il est convenu que, conformément à l'article 89 du Règlement, le président soit autorisé à tenir des réunions pour entendre des témoignages et à en permettre la publication en l'absence de quorum, pourvu qu'un représentant du gouvernement et un représentant de l'opposition soient présents.

Il est convenu que le comité adopte l'ébauche du premier rapport, rédigée conformément à l'article 104 du Règlement et que le président dépose le rapport à la prochaine séance du Sénat.

It was agreed that the chair, on behalf of the committee, ask the Library of Parliament to assign research analysts to the committee.

It was agreed that the chair be authorized to seek authority from the Senate to engage the services of such counsel and technical, clerical and other personnel as may be necessary for the purpose of the committee's examination and consideration of such bills, subject-matters of bills and estimates as are referred to it.

It was agreed that the Subcommittee on Agenda and Procedure be authorized to retain the services of such experts as may be required by the work of the committee; and

That the chair, on behalf of the committee, direct the research staff in the preparation of studies, analyses, summaries and draft reports.

It was agreed that, pursuant to section 32 of the Financial Administration Act, and Section 7, Chapter 3:06 of the *Senate Administrative Rules*, authority to commit funds be conferred individually on the chair, the deputy chair and the clerk of the committee; and

That, pursuant to section 34 of the Financial Administration Act, and Section 8, Chapter 3:06 of the *Senate Administrative Rules*, authority for certifying accounts payable by the committee be conferred individually on the chair, the deputy chair, and the clerk of the committee.

It was agreed that the committee empower the chair and deputy chair, as required, one or more members of the committee and/or such staff as may be necessary to travel on assignment on behalf of the committee.

It was agreed that the chair and deputy chair be authorized to:

1) determine whether any member of the committee is on "official business" for the purposes of paragraph 8(3)(a) of the Senators Attendance Policy, published in the *Journals of the Senate* on Wednesday, June 3, 1998; and

2) consider any member of the committee to be on "official business" if that member is: (a) attending a function, event or meeting related to the work of the committee; or (b) making a presentation related to the work of the committee.

It was agreed that, pursuant to the Senate guidelines for witnesses expenses, the committee may reimburse reasonable travelling and living expenses for one witness from any one organization and payment will take place upon application, but that the chair be authorized to approve expenses for a second witness should there be exceptional circumstances.

It was agreed that the chair be authorized to seek authority from the Senate to permit coverage by electronic media of the committee's public proceedings with the least possible disruption of its hearings; and

Il est convenu que le président, au nom du comité, demande à la Bibliothèque du Parlement de lui affecter des attachés de recherche.

Il est convenu que le président soit autorisé à demander au Sénat la permission de retenir les services de conseillers juridiques, de techniciens, d'employés de bureau et d'autres personnes, au besoin, pour aider le comité à examiner les projets de loi, l'objet de ces derniers et les prévisions budgétaires qui lui sont renvoyés.

Il est convenu que le Sous-comité du programme et de la procédure soit autorisé à faire appel aux services des experts-conseils dont le comité peut avoir besoin dans le cadre de ses travaux; et

Que le président, au nom du comité, dirige le personnel de recherche dans la préparation d'études, d'analyses, de résumés et de projets de rapport.

Il est convenu que, conformément à l'article 32 de la Loi sur la gestion des finances publiques et à l'article 7, chapitre 3:06, du *Règlement administratif du Sénat*, l'autorisation d'engager les fonds du comité soit conférée individuellement au président, au vice-président et au greffier du comité; et

Que, conformément à l'article 34 de la Loi sur la gestion des finances publiques et à l'article 8, chapitre 3:06, du *Règlement administratif du Sénat*, l'autorisation d'approuver les comptes à payer au nom du comité soit conférée individuellement au président, au vice-président et au greffier du comité

Il est convenu que le comité autorise le président et le vice-président à désigner, au besoin, un ou plusieurs membres du comité, de même que le personnel nécessaire, qui se déplaceront au nom du comité.

Il est convenu que le président et le vice-président soient autorisés à:

1) déterminer si un membre du comité accomplit un « engagement officiel » aux fins de l'alinéa 8(3)a) de la politique relative à la présence des sénateurs, publiée dans les *Journaux du Sénat* du mercredi 3 juin 1998; et

2) considérer qu'un membre du comité accomplit un « engagement officiel » si ce membre: a) exerce une fonction ou assiste à une activité ou à une réunion se rapportant aux travaux du comité; ou b) fait un exposé ayant trait aux travaux du comité.

Il est convenu que, conformément aux lignes directrices concernant les frais de déplacement des témoins, le comité rembourse les dépenses raisonnables de voyage et d'hébergement à un témoin par organisme, après qu'une demande de remboursement a été présentée, mais que le président soit autorisé à permettre le remboursement de dépenses à un deuxième témoin de ce même organisme en cas de circonstances exceptionnelles.

Il est convenu que le président soit autorisé à demander au Sénat la permission de diffuser ses délibérations publiques par les médias d'information électronique, de manière à déranger le moins possible ses travaux; et

That the Subcommittee on Agenda and Procedure be empowered to allow such coverage at its discretion.

At 8:20 a.m., it was agreed that the committee adjourn to the call of the chair.

*ATTEST:*

*La greffière du comité,*

Josée Thérien

*Clerk of the Committee*

Que le Sous-comité du programme et de la procédure soit autorisé à permettre cette diffusion à sa discrétion.

À 8 h 20, il est convenu que le comité suspende ses travaux jusqu'à nouvelle convocation de la présidence.

*ATTESTÉ:*

**REPORT OF THE COMMITTEE**

Tuesday, April 25, 2006

The Standing Senate Committee on Social Affairs, Science and Technology has the honour to table its

**FIRST REPORT**

Your Committee, which was authorised by the Senate to incur expenses for the purpose of its examination and consideration of such legislation and other matters as were referred to it, reports, pursuant to rule 104, that the expenses incurred by the Committee during the First Session of the Thirty-eighth Parliament are as follow:

1. With respect to its examination and consideration of legislation:

Professional and Other Services	\$ —
Transport and Communications	\$ 5,111.53
Other Expenditures	\$ —
Witness Expenses	\$ 2,989.00
<b>Total</b>	<b>\$ 8,100.53</b>

2. With respect to its special study on mental health and mental illness:

Professional and Other Services	\$ 251,968.51
Transport and Communications	\$ 167,840.33
Other Expenditures	\$ 14,124.95
Witness Expenses	\$ 54,196.00
<b>Total</b>	<b>\$ 488,129.79</b>

During the session in question, your Committee received 14 orders of reference, held 58 meetings, and received evidence from 330 witnesses over a period of approximately 137 hours. Twelve bills were referred to the Committee. In total, your Committee produced 16 reports.

Respectfully submitted,

*Le président,*

**MICHAEL KIRBY**

*Chair*

**RAPPORT DU COMITÉ**

Le mardi 25 avril 2006

Le Comité sénatorial permanent des Affaires sociales, des sciences et de la technologie a l'honneur de déposer son

**PREMIER RAPPORT**

Votre Comité, qui a été autorisé par le Sénat à engager des dépenses afin d'étudier les mesures législatives et autres questions qui lui ont été renvoyées, dépose, conformément à l'article 104 du Règlement, le relevé suivant des dépenses qu'il a faites à cette fin au cours de la première session de la trente-huitième législature:

1. Relativement à son étude des mesures législatives:

Services professionnels et autres	— \$
Transport et communications	5 111,53 \$
Autres dépenses	— \$
Dépenses des témoins	2 989,00 \$
<b>Total</b>	<b>8 100,53 \$</b>

2. Relativement à son étude spéciale sur la santé mentale et la maladie mentale:

Services professionnels et autres	251 968,51 \$
Transport et communications	167 840,33 \$
Autres dépenses	14 124,95 \$
Dépenses des témoins	54 196,00 \$
<b>Total</b>	<b>488 129,79 \$</b>

Durant la session en cause, le Comité a reçu 14 ordres de renvoi, tenu 58 réunions et entendu 330 témoins sur une période d'approximativement 137 heures. Il a été saisi de douze projets de loi. Au total, le Comité a produit 16 rapports.

Respectueusement soumis,

**EVIDENCE**

OTTAWA, Tuesday, April 25, 2006

The Standing Senate Committee on Social Affairs, Science and Technology met this day at 8:04 a.m., pursuant to rule 88 of the *Rules of the Senate*, to organize the activities of the committee.

[English]

**Ms. Josée Thérien, Clerk of the Committee:** Honourable senators, we have a quorum. As clerk of your committee, it is my duty to preside over the election of the chair. I am ready to receive nominations to that effect.

**Senator Cochrane:** I nominate Senator Kirby.

**Ms. Thérien:** Will there be any other nominations? It is moved by the Honourable Senator Cochrane that the Honourable Senator Kirby be chair of this committee. Is it your pleasure, honourable senators, to adopt the motion?

**Hon. Senators:** Agreed.

**Ms. Thérien:** I declare the motion carried. In accordance with rule 88 the Honourable Senator Kirby is elected chair of this committee.

**The Chairman:** Next we need a motion for the vice chair. Are there any further nominations? Then I declare Senator Keon elected deputy chair. Finally, we need a motion to nominate a third person.

**Senator Fairbairn:** Senator Pépin.

**The Chairman:** Senator Pépin is nominated to be the third person on the steering committee. Are there any other nominations? I declare that carried.

You have in front of you, starting with number 4 — this is to save me having to read them all out — a motion to print the committee's proceedings. Can we pass that? Number five is the authorization to hold meetings and to print evidence when a quorum is not present. Are there any objections to that one?

The next is a financial report. This is the first report, on the expenditures of last year. I presume we will also report that, since the money is already spent; is that correct? I will table that in the chamber this afternoon.

Number 7 at the top of page 3 is the one that Howard does not get to vote on because in it we ask him to continue acting as our chief researcher. We do not want to give Howard a vote because we are afraid he will vote against it. Are we agreed?

**Hon. Senators:** Agreed.

**The Chairman:** Number 8 is the authority to commit funds and certify counsel. It gives the authority to the steering committee and the clerk to spend money that we are given under the budget. Is that one all right?

**TÉMOIGNAGES**

OTTAWA, le mardi 25 avril 2006

Le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie se réunit aujourd'hui à 8 h 4, conformément à l'article 88 du *Règlement du Sénat*, afin d'organiser ses activités.

[traduction]

**Josée Thérien, greffière du comité:** Honorables sénateurs, je constate que nous avons le quorum. En ma qualité de greffière de votre comité, il m'incombe de présider à l'élection d'un président. Je suis prête à recevoir les motions à cet effet.

**Le sénateur Cochrane:** Je propose la candidature du sénateur Kirby.

**Mme Thérien:** Y aura-t-il d'autres candidatures? L'honorable sénateur Cochrane propose que l'honorable sénateur Kirby soit élu au poste de président du comité. Vous plaît-il, honorables sénateurs, d'adopter la motion?

**Des voix:** D'accord.

**Mme Thérien:** Je déclare la motion adoptée. En vertu de l'article 88 du Règlement, l'honorable sénateur Kirby est dûment élu président du comité.

**Le président:** Il nous faut maintenant une motion pour l'élection du vice-président. Y a-t-il des candidatures? Alors je déclare le sénateur Keon élu vice-président. Pour terminer, il nous faut une motion pour désigner une troisième personne.

**Le sénateur Fairbairn:** Le sénateur Pépin.

**Le président:** On propose le sénateur Pépin comme troisième membre du comité de direction. Y a-t-il d'autres candidatures? Je déclare la motion adoptée.

Vous avez devant vous, en commençant avec le numéro 4 — cela m'épargnera leur lecture à haute voix — une motion pour l'impression des délibérations du comité. Pouvons-nous l'adopter? Le numéro cinq est l'autorisation de tenir des réunions et d'imprimer les témoignages en l'absence de quorum. Y a-t-il des objections à cela?

Vient ensuite le rapport financier. C'est le premier rapport sur les dépenses de l'année dernière. Je présume que nous allons aussi en faire rapport, puisque les dépenses sont faites, n'est-ce pas? Je le présenterai à la Chambre cet après-midi.

La motion numéro 7, au haut de la page 3, est celle pour laquelle Howard n'est pas autorisé à voter parce que c'est celle où on lui demande de continuer d'assumer les fonctions de notre chercheur en chef. Nous ne voulons pas lui accorder le droit de vote sur cette motion, de crainte qu'il s'y oppose. Sommes-nous d'accord?

**Des voix:** D'accord.

**Le président:** Au numéro 8, c'est l'autorisation d'engager des fonds et d'approuver les comptes à payer. Cela permet au comité directeur et au greffier d'engager les fonds qui nous sont accordés pour le budget. Est-ce que ça va?

**Hon. Senators:** Agreed.

**The Chairman:** Then there is the travel one, which allows the steering committee to designate people to travel on behalf of the committee. So far, we have not really used that, but I suppose it is one that we ought to put in there. Is everybody okay with that one?

**Hon. Senators:** Agreed.

**The Chairman:** Number 10 deals with the issue of whether you are away on official business or not. The way this committee has operated for a decade or so has been that it is decided between the chair and the deputy chair. If people are away on business, giving a speech on behalf of the committee or whatever, all they need to do is phone my office or Senator Keon's office and we have a process to inform the clerk. Therefore, you are marked as being away on Senate business rather than public business. Are we agreed on that one?

**Hon. Senators:** Agreed.

**The Chairman:** The one on travelling and living expenses of witnesses is the standard motion relating to people we have invited to come to speak.

Regarding the electronic media coverage of public meetings, as you know, this committee was the first one in the Senate to have a blanket authorization that if CPAC wants to cover us, they can do so. Lots of times they do not; lots of times they do. Originally, we had to go back to the chamber each time and ask. That did not make sense because sometimes we would have witnesses that suddenly CPAC wanted to cover. This is the blanket authorization on media coverage, if we want to do that. Are we okay on that?

The final point is that the time slot for our meetings has not changed. It is Wednesday afternoon and the latter part of Thursday morning.

There are two other items to talk about on the mental health report. Now that we have been officially created, we will have pacified the Deputy Leader of the Opposition. Therefore, we can pass Senator Keon's motion this afternoon, the one referring back to the committee the mental health reference from the last two times we have had a session. We will get that through this afternoon.

Then we will meet tomorrow. Let us talk about that for a second. Except for Senators Eggleton and Forrestall, all the rest of you were on the previous committee. As you know, we have gone through and signed off on the mental health report due to be released on Tuesday, May 9. The only item on the agenda tomorrow — hopefully it will be just a 60-second item — will say that we have approved the final text of the report. Everybody on the old committee has gone through it repeatedly and signed off on it, including people like Senator Gill who are no longer on this committee. There has been a slight change. The process will require that we meet tomorrow to formally adopt the committee

**Des voix:** D'accord.

**Le président:** Et puis il y a la motion sur les voyages, qui permet au comité directeur de désigner les personnes qui se déplaceront au nom du comité. Jusqu'à maintenant, nous n'avons pas usé de ce pouvoir, mais je suppose que nous devons passer par cette motion. Est-ce que tout le monde est d'accord?

**Des voix:** D'accord.

**Le président:** Le numéro 10 est pour déterminer si vous êtes en engagement officiel ou non. Pendant des décennies, la façon dont a fonctionné le comité est que c'était décidé entre le président et le vice-président. Si des membres allaient en voyage officiel pour prononcer une allocution au nom du comité ou autre chose, il leur suffisait de téléphoner à mon bureau ou à celui du sénateur Keon et nous avons une procédure pour informer le greffier. Ainsi, il est inscrit que vous êtes en déplacement pour le compte du Sénat plutôt que pour un engagement public. Sommes-nous d'accord là-dessus?

**Des voix:** D'accord.

**Le président:** La motion sur les dépenses de voyage et de séjour est la motion standard concernant les personnes que nous invitons à venir nous parler.

En ce qui concerne la diffusion par les médias électroniques des réunions publiques, comme vous le savez, ce comité a été le premier comité du Sénat à accorder une autorisation générale donnant toute liberté à la chaîne CPAC de diffuser quand elle le souhaite. Bien souvent elle ne le fait pas, et bien souvent elle le fait. À l'origine, nous devions retourner à la Chambre chaque fois pour poser la question. Ce n'était pas bien logique parce qu'il arrivait que nous entendions des témoignages que, soudainement, la chaîne CPAC voulait diffuser. Ce que nous avons ici, c'est l'autorisation générale de diffusion par les médias, si nous voulons l'accorder. Sommes-nous d'accord avec ceci?

Le dernier point est que la plage horaire, pour nos réunions, n'a pas changé. C'est le mercredi après-midi et la fin de la matinée du jeudi.

Il y a deux autres questions dont nous devons parler, à propos du rapport sur la santé mentale. Maintenant que notre comité est officiellement constitué, nous aurons apaisé le leader adjoint de l'opposition. Par conséquent, nous pouvons adopter la motion du sénateur Keon cet après-midi, celle de renvoi au comité de la référence relative à la santé mentale, découlant des deux dernières fois que nous nous sommes réunis. Nous réglerons cela cet après-midi.

Et puis nous allons nous réunir demain. Parlons-en un moment. À l'exception des sénateurs Eggleton et Forrestall, vous étiez tous membres du comité auparavant. Comme vous le savez, nous avons examiné et approuvé le rapport sur la santé mentale qui doit être publié le mardi 9 mai. La seule question à l'ordre du jour demain — espérons qu'il ne faudra pas plus d'une minute pour la régler — est pour dire que nous avons approuvé la version finale du rapport. Tous les membres de l'ancien comité l'ont examiné en profondeur et approuvé, y compris des gens comme le sénateur Gill, qui ne siège plus au comité. Il y a eu une petite modification. Le processus exige que nous nous

report. That will be the only agenda item. Senator Keon will be in the chair. I am chairing a mental health meeting in Toronto all day tomorrow and tomorrow evening. Since we all signed off on the report, I am assuming that is not a problem.

Let me raise just a couple of other issues on communications with respect to the report. Thank goodness it is getting out. The pressure from the mental health community has been enormous.

We are doing much of what we did last time. We will have an op-ed piece. I know the Atlantic senators signed one collectively and sent it to all the papers. You will receive calls from my office about trying to visit the editorial boards in each of your respective provinces, to the extent that you can.

We have done some overheads that will be available to everyone who wants to make a speech. We will give you a text if you need it, but you can just use the overheads. There is a general set, but we will give you an additional piece if you are talking to a children's audience or a seniors' audience or a workplace audience. We have one that deals with the overall report, and then you slot in the target piece for the particular audience. People want to know the overview plus the particular items. The overview piece is available; and as soon as we know you have a speaking engagement with a particular type of audience, we will give you those.

My guess, on the basis of the requests we have had so far, is that all of you will have to pick up some speaking engagements because two or three of us just cannot do it. The number of people in the mental health community in various positions who want to hear first-hand from somebody on the committee is large. We have an obligation now to get out and get it done.

Finally, you will recall that the Canadian mental health commission, which had been approved by the provinces and territories and the federal government previously, has also been approved by the current government. The Canadian mental health commission will, in fact, be created exactly along the lines that we have talked about. Are there any questions?

**Senator Trenholme Counsell:** Did the government agree on the mental health commission?

**The Chairman:** What they will do with that is what they have done with CIHI, the Canadian Institute of Health Information. They are sending an official observer to act, *de facto*, as a person on the board, but they will still say they did not recognize it. The only reason for that is they argue health is a provincial responsibility. On the other hand, the Minister of Health and the Assistant Deputy Minister of Health both told me they agree absolutely with the terms of reference.

rencontrions demain pour adopter officiellement le rapport du comité. Ce sera le seul point à l'ordre du jour. Le sénateur Keon occupera le fauteuil. Je sois assumer la présidence d'une réunion sur la santé mentale à Toronto, qui dure toute la journée et la soirée de demain. Puisque nous avons tous approuvé le rapport, je suppose que cela ne pose pas de problème.

Permettez-moi de soulever une ou deux autres questions sur les communications en ce qui concerne le rapport. Dieu merci, il sera enfin diffusé. La communauté de la santé mentale a exercé d'intenses pressions.

Nous faisons à peu près la même chose que la dernière fois. Nous aurons un article voisin de la page éditoriale. Je sais que les sénateurs de l'Atlantique ont approuvé le rapport collectivement et l'ont envoyé à tous les journaux. Vous recevrez des appels de mon bureau pour vous inciter à rendre visite aux comités de rédaction de chacune de vos provinces respectives, autant que possible.

Nous avons préparé quelques acétates, qui seront à la disposition de quiconque voudra prononcer une allocution. Nous vous donnerons un texte si vous en avez besoin, mais vous pouvez n'utiliser que les acétates. Il y a une série générale, mais nous vous remettons une série additionnelle si vous parlez devant un public d'enfants ou de personnes âgées, ou dans un milieu de travail. Nous en avons une qui traite du rapport dans son ensemble, dans laquelle vous pouvez insérer la série axée sur le public particulier. Les gens veulent un tableau d'ensemble, plus les aspects spécifiques. La série d'acétates sur le tableau d'ensemble est disponible; dès que nous saurons que vous devez vous adresser à un public particulier, nous vous remettons la série qui s'y rapporte.

À mon avis, d'après les demandes que nous avons reçues jusqu'à maintenant, vous devrez tous accepter de présenter des exposés parce qu'à deux ou trois seulement, nous n'y arriverons pas. Il y a beaucoup de membres de la communauté de la santé mentale, occupant diverses fonctions, qui veulent entendre en personne un membre du comité parler du rapport. Nous avons une obligation, maintenant, de le faire.

Enfin, vous vous rappelez certainement la commission canadienne de la santé mentale, dont les provinces et territoires et le gouvernement fédéral ont déjà approuvé la création? Le gouvernement actuel a aussi donné son accord. Alors la commission canadienne de la santé mentale sera, en fait, créée exactement sur le modèle dont nous avons discuté. Y a-t-il des questions?

**«Le sénateur Trenholme Counsell:** Est-ce que le gouvernement a approuvé la création de la commission de la santé mentale?

**Le président:** Ce qu'ils feront, c'est la même chose que pour l'ICIS, l'Institut canadien d'information sur la santé. Ils enverront un observateur officiel qui agira, *de facto*, comme un membre du comité, mais ils le nieront. La seule raison à cela est qu'ils soutiennent que la santé est une responsabilité provinciale. D'un autre côté, le ministre et le sous-ministre de la Santé m'ont tous deux dit qu'ils sont tout à fait d'accord avec le mandat.

De jure they are not members, but de facto they are. Since we were not asking them for any money, it is not an issue.

**Senator Pépin:** This book is from Dr. Yves Lamontagne. It deals with the health system and making a decision on health systems. I received it just this morning.

**The Chairman:** I spent yesterday with Michel Claire, who did the Claire commission's report in Quebec. We were on a panel together. His views are identical to ours, including on what needs to be done in mental health. He is a smart man.

I think the answer to your question is that we will play the game. The answer is that formally, the Quebec government has not signed on. Informally, they will be as active participants as they are in the other national health groups. Every other province and territory is onside.

Senator Keon, is there anything we need to add?

**Senator Keon:** The minister asked us for a list of names for the commission.

**The Chairman:** Yes. If you send the names to my office, I will compile a list. I have a thick pile of letters that were sent unsolicited to my office. If you send me names, I will break them out geographically and by area of interest.

I think that anyone who is asked to be on this commission will agree to serve. The level of interest is high. This is not a case where we will have to twist arms to get people to do it. The problem is that we will have 300 people for 12 spots.

There is a woman in Manitoba nominated by Ed Schryer. He has a son who has schizophrenia, which I did not know. He sent me a personal note saying that he would be more than glad to do anything he could to assist. The person he nominated has nothing to do with politics; it is just someone he knows. The previous Conservative Premier of Manitoba sent me the same letter, so we know it is not political. It is amazing what you learn as you go down the road.

We will pass Senator Keon's motion this afternoon and have a brief meeting tomorrow here at the adjournment of the Senate. Senator Keon will be in the chair. You will receive all the material from my office next week so that you will have it in advance to review.

The clerk will distribute copies of the final report. Regardless of Senate procedures, I did tell the federal, provincial and territorial ministers of health that I would send them a copy in the middle of next week so that they are not blind-sided.

**Senator Cook:** You are sending a copy to our Minister of Health?

Ils jurent ne pas être membres, mais en fait ils le sont. Comme ils ne demandent pas d'argent, cela ne pose pas de problème.

**Le sénateur Pépin:** Ce livre est du Dr Yves Lamontagne. Il traite du système de santé et de la nécessité de prendre une décision à son sujet. Je viens de le recevoir, ce matin.

**Le président:** J'ai passé la journée, hier, avec Michel Claire, qui a rédigé le rapport de la commission Claire au Québec. Nous siégeons ensemble. Des opinions sont identiques aux nôtres, y compris sur ce qui doit être fait au sujet de la santé mentale. C'est un homme intelligent.

Je pense que la réponse à votre question est que nous jouerons le jeu. La réponse est qu'officiellement, le gouvernement du Québec n'a pas donné son accord. Officieusement, ils seront des participants actifs, comme ils le sont au sein d'autres groupes nationaux sur la santé. Tous les autres territoires et provinces sont avec nous.

Sénateur Keon, y a-t-il quelque chose à ajouter?

**Le sénateur Keon:** Le ministre nous a demandé une liste de noms pour la commission.

**Le président:** Oui. Si vous envoyez les noms à mon bureau, je dresserai une liste. J'ai une épaisse pile de lettres qui ont été envoyées sans invitation à mon bureau. Si vous m'envoyez des noms, je ferai une répartition par région géographique et par secteurs d'intérêt.

Je pense que quiconque s'intéresse à cette commission sera d'accord pour y siéger. Elle suscite un grand intérêt. Ce n'est pas un cas où nous devons tordre des bras pour que des gens acceptent d'y siéger. Le problème, c'est que nous aurons 300 candidatures pour douze places.

Il y a une femme du Manitoba, que propose Ed Schryer. Il a un fils schizophrène, et je ne le savais pas. Il m'a envoyé une note personnelle disant qu'il ferait volontiers tout ce qu'il peut pour aider. La personne dont il propose la candidature n'a rien à voir avec la politique; c'est simplement quelqu'un qu'il connaît. L'ex-premier ministre conservateur du Manitoba m'a envoyé la même lettre, alors nous savons que ce n'est pas politique. C'est incroyable ce qu'on peut apprendre, au fil des événements.

Nous voterons sur la motion du sénateur Keon cet après-midi, puis nous aurons une brève réunion demain, ici, après l'ajournement du Sénat. Le sénateur Keon occupera le fauteuil. Vous recevrez des documents de mon bureau la semaine prochaine, et ainsi vous aurez la possibilité de les lire à l'avance.

La greffière distribuera des copies du rapport final. Quelles que soient les procédures du Sénat, j'ai dit aux ministres de la Santé fédéral, provinciaux et territoriaux que je leur en enverrai une copie au milieu de la semaine prochaine pour qu'ils ne soient pas pris par surprise.

**Le sénateur Cook:** Vous en envoyez une copie à notre ministre de la Santé?

**The Chairman:** Yes, and to the deputy. What will they do if this lands on their desks and a media person asks them about it? It is a courtesy. They are embargoed; they are used to dealing with them.

The committee adjourned.

**Le président:** Oui, et aussi au sous-ministre. Que feront-ils si cela atterrit sur leur bureau et qu'un membre des médias leur pose des questions là-dessus? C'est par simple courtoisie. Ils font l'objet d'un embargo; ils sont habitués à cela.

La séance est levée.

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First Session  
Thirty-ninth Parliament, 2006

Première session de la  
trente-neuvième législature, 2006

## SENATE OF CANADA

## SÉNAT DU CANADA

*Proceedings of the Standing  
Senate Committee on*

*Délibérations du Comité  
sénatorial permanent des*

# Social Affairs, Science and Technology

# Affaires sociales, des sciences et de la technologie

*Chair:*

The Honourable MICHAEL KIRBY

*Président :*

L'honorable MICHAEL KIRBY

Monday, May 8, 2006

Le lundi 8 mai 2006

**Issue No. 2  
Volume 1 of 5**

**Fascicule n° 2  
Volume 1 de 5**

**SECOND REPORT OF THE COMMITTEE**  
(Final report on mental health,  
mental illness and addiction entitled:  
**OUT OF THE SHADOWS AT LAST**  
*Transforming Mental Health, Mental Illness  
and Addiction Services in Canada —  
Introduction, Parts I and II*)

**DEUXIÈME RAPPORT DU COMITÉ**  
(Rapport final sur la santé mentale,  
la maladie mentale et la toxicomanie intitulé :  
**DE L'OMBRE À LA LUMIÈRE**  
*La transformation des services concernant la santé mentale,  
la maladie mentale et la toxicomanie au Canada —  
Introduction, parties I et II*)

THE STANDING SENATE COMMITTEE  
ON SOCIAL AFFAIRS, SCIENCE  
AND TECHNOLOGY

The Honourable Michael Kirby, *Chair*

The Honourable Wilbert J. Keon, *Deputy Chair*

and

The Honourable Senators:

Callbeck	Forrestall
Champagne, P.C.	* Hays
Cochrane	(or Fraser)
Cook	* LeBreton, P.C.
Cordy	(or Comeau)
Eggleton, P.C.	Pépin
Fairbairn, P.C.	Trenholme Counsell

\*Ex officio members

(Quorum 4)

LE COMITÉ SÉNATORIAL PERMANENT  
DES AFFAIRES SOCIALES, DES SCIENCES  
ET DE LA TECHNOLOGIE

*Président* : L'honorable Michael Kirby

*Vice-président* : L'honorable Wilbert J. Keon

et

Les honorables sénateurs :

Callbeck	Forrestall
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Cordy	(ou Comeau)
Eggleton, C.P.	Pépin
Fairbairn, C.P.	Trenholme Counsell

\*Membres d'office

(Quorum 4)

**REPORT OF THE COMMITTEE**

Monday, May 8, 2006

The Senate Committee on Social Affairs, Science and Technology has the honour to table its

**SECOND REPORT**

Your Committee, which was authorized by the Senate on Tuesday, April 25, 2006 to examine and report on issues concerning mental health and mental illness, now tables its final report entitled: *Out of the Shadows at Last*.

Respectfully submitted,

*Le président,*

MICHAEL KIRBY

*Chair*

**RAPPORT DU COMITÉ**

Le lundi 8 mai 2006

Le Comité sénatorial des affaires sociales, des sciences et de la technologie a l'honneur de déposer son

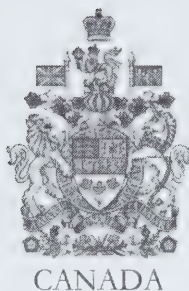
**DEUXIÈME RAPPORT**

Votre Comité, qui a été autorisé par le Sénat le mardi 25 avril 2006 à examiner, pour en faire rapport, la santé mentale et la maladie mentale; dépose maintenant son rapport final intitulé : *De l'ombre à la lumière*.

Respectueusement soumis,



The Senate



Le Sénat

# OUT OF THE SHADOWS AT LAST

## *Transforming Mental Health, Mental Illness and Addiction Services in Canada*

Final Report of  
The Standing Senate Committee on Social Affairs, Science and Technology

The Honourable Michael J.L. Kirby, Chair  
The Honourable Wilbert Joseph Keon, Deputy Chair

May 2006

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(Committee Business — Senate — Recent Reports)

38<sup>th</sup> Parliament — 1st Session

The Standing Senate Committee on Social Affairs, Science and Technology

Final Report on  
Mental Health, Mental Illness and Addiction

# OUT OF THE SHADOWS AT LAST

TRANSFORMING MENTAL HEALTH, MENTAL ILLNESS  
AND ADDICTION SERVICES IN CANADA

*Chair*

The Honourable Michael J.L. Kirby

*Deputy Chair*

The Honourable Wilbert Joseph Keon

May 2006



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## **PART VI**

### **STRATEGIC PLANNING AND INTER-GOVERNMENTAL COORDINATION**

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## ORDER OF REFERENCE

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Extract from the *Journals of the Senate* for Thursday, October 7, 2004:

The Honourable Senator Kirby moved, seconded by the Honourable Losier-Cool:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness.

That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh Parliament be referred to the Committee; and

That the Committee submit its final report no later than December 16, 2005 and that the Committee retain all powers necessary to publicize the findings of the Committee until March 31, 2006.

The question being put on the motion, it was adopted.

---

Extract from the *Journals of the Senate* for Thursday, October 20, 2005:

The Honourable Senator Kirby moved, seconded by the Honourable Senator Pépin:

That, notwithstanding the Order of the Senate adopted on Thursday, October 7, 2004, the Standing Senate Committee on Social Affairs, Science and Technology, which was authorized to examine and report on issues arising from, and development since, the tabling of its final report on the state of the health care system in Canada in October 2002 (mental health and mental illness), be empowered to present its final report no later than June 30, 2006, and that the Committee retain all powers necessary to publicize the findings of the Committee contained in the final report until October 31, 2006; and

That the Committee be permitted, notwithstanding usual practices, to deposit any report with the Clerk of the Senate, if the Senate is not then sitting; and that the report be deemed to have been tabled in the Chamber.

After debate,

The question being put on the motion, it was adopted.

---

Extract from the *Journals of the Senate* of Tuesday, April 25, 2006:

The Honourable Senator Keon moved, seconded by the Honourable Senator Stratton:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on issues arising from, and developments since, the tabling of its final report on the state of the health care system in Canada in October 2002. In particular, the Committee shall be authorized to examine issues concerning mental health and mental illness;

That the papers and evidence received and taken by the Committee on the study of mental health and mental illness in Canada in the Thirty-seventh and Thirty-eighth Parliaments be referred to the Committee;

That the Committee submit its final report no later than June 30, 2006 and that the Committee retain all powers necessary to publicize the findings of the Committee until September 30, 2006; and

That the Committee be permitted, notwithstanding usual practices, to deposit any report with the Clerk of the Senate, if the Senate is not then sitting; and that the report be deemed to have been tabled in the Chamber.

Paul C. Bélisle  
*Clerk of the Senate*

The following Senators have participated in the study on mental health and mental illness of the Standing Senate Committee on Social Affairs, Science and Technology:

The Honourable Michael J. L. Kirby, Chair of the Committee

The Honourable Wilbert Joseph Keon, Deputy Chair of the Committee

The Honourable Senators:

Catherine S. Callbeck

Andrée Champagne

Ethel M. Cochrane

Joan Cook

Jane Mary Cordy

Art Eggleton

Joyce Fairbairn, P.C.

J. Michael Forrestall

Aurélien Gill

Marjory LeBreton

Viola Léger (retired)

Yves Morin (retired)

Lucie Pépin

Brenda Robertson (retired)

Marilyn Trenholme Counsell

*Ex-officio members of the Committee:*

The Honourable Senators: Jack Austin P.C. or (William Rompkey) and Noël A. Kinsella or (Terrance Stratton)

*Other Senators who have participated from time to time on this study:*

The Honourable Senators Di Nino, Dyck, Johnson, Kinsella, Lynch-Staunton, Mercer, Milne, Murray, Pearson, St.Germain, Stratton and Tardif.

## ACKNOWLEDGEMENTS

---

The Committee wants to publicly acknowledge the enormous assistance it has received during the past two years from those who have worked so hard in helping the Committee to produce its reports on Mental Health, Mental Illness and Addiction.

In particular, the Committee wants to express its deep appreciation to the following people:

Dr. Howard Chodos and Mr. Tim Riordan Raaflaub of Parliamentary Information and Research Service, the full-time research staff of the Committee, have been deeply involved in all drafts of the reports that the Committee produced during this study. Mrs. Odette Madore was a key researcher on our first three reports on Mental Health and Dr. Nancy Miller Chenier was heavily involved in this final volume. The Committee is also grateful to the numerous other researchers from the Parliamentary Information and Research Service who worked on many of the individual chapters in this report. Without all their extraordinary help and commitment these reports would not have been completed in such a short time, nor in such a competent manner.

Josée Thérien, the Committee Clerk and her assistant, Louise Pronovost, were responsible for organizing all the meetings the Committee held on Mental Health, Mental Illness and Addiction, including scheduling the appearances of all the witnesses, for overseeing the translation and printing of all the reports, and for responding to thousands of requests for information about the Committee's work and for copies of the Committee's reports.

Dr. Duncan Sinclair, the former chair of the Health Services Restructuring Commission of Ontario, who without failure, gave generously of his time. His expertise, support and advice was welcomed and appreciated throughout the Committee's study.

We also want to thank the staff of each of the members of the Committee, who have had to endure a substantially increased work load over the past two years.

Thanks is also owed to Steve Lurie, for his extraordinary assistance on many of the technical aspects and cost estimates used in the report.

Also to Dr. David Goldbloom for his wise advice and counsel.

The Committee is indebted to Sheryl Pedersen, author of "Emmy's Story," which comprises the epilogue of this report.

To all of these people, we express our heartfelt thanks for a job very well done.

The Committee worked long hours over many months, requiring the services of a large number of procedural, research and administrative officers, editors, reporters, interpreters, translators, messengers, publications, broadcasting, printing, technical and logistical staff who ensured the progress of the work and reports of the Committee. We wish to extend our appreciation for their efficiency and hard work.

In *More for the Mind*, a study of psychiatric services in Canada, the Canadian Mental Health Association said:

In no other field, except perhaps leprosy, has there been as much confusion, misdirection and discrimination against the patient, as in mental illness... Down through the ages, they have been estranged by society and cast out to wander in the wilderness. Mental illness, even today, is all too often considered a crime to be punished, a sin to be expiated, a possessing demon to be exorcised, a disgrace to be hushed up, a personality weakness to be deplored or a welfare problem to be handled as cheaply as possible.<sup>1</sup>

These words were written nearly half a century ago. Yet the more than two thousand personal stories submitted to the Standing Senate Committee on Social Affairs, Science and Technology by Canadians living with mental illness, and their families, make clear that these words continue to ring true.

It was difficult emotionally for Committee members to hear these stories. Listening to them, and reading them, had a profound effect on every one of us. As the months passed, they began to tear at our souls.

Committee members could relate to these stories because of their own personal experiences. Like any group of a dozen Canadians, we too have experienced the impact of mental illness in our families: a sister-in-law who has schizophrenia, a nephew who committed suicide, a daughter who battled anorexia for several years, a sister who lives with severe depression and has been in and out of psychiatric hospitals frequently; it is rare that a family has not been affected.

Indeed, it is this personal experience that has caused Committee members to regard our work on this report as much more than just another policy study: to us, it is truly a calling.

We know how difficult it will be to improve the lives of people living with mental illness. We know it will be tougher still to change deep-seated public attitudes and reduce the stigma and discrimination they face. To put each of them on the road to recovery will be an extraordinary challenge.

Yet we are optimistic that the time has come when meaningful change can, and will, be made. From coast to coast we have met politicians, government officials, mental health service providers and professionals, and many, many ordinary Canadians, who are willing to help make change a reality, to help bring people living with mental illness into the mainstream of Canadian society.

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<sup>1</sup> Canadian Mental Health Association, (1963) *More for the Mind: A Study of Psychiatric Services in Canada*, Toronto, p. 1.

We ask the readers of this report to join with us as, together, we work to transform mental health, mental illness and addiction services in Canada and to bring mental illness *Out of the Shadows at Last*.

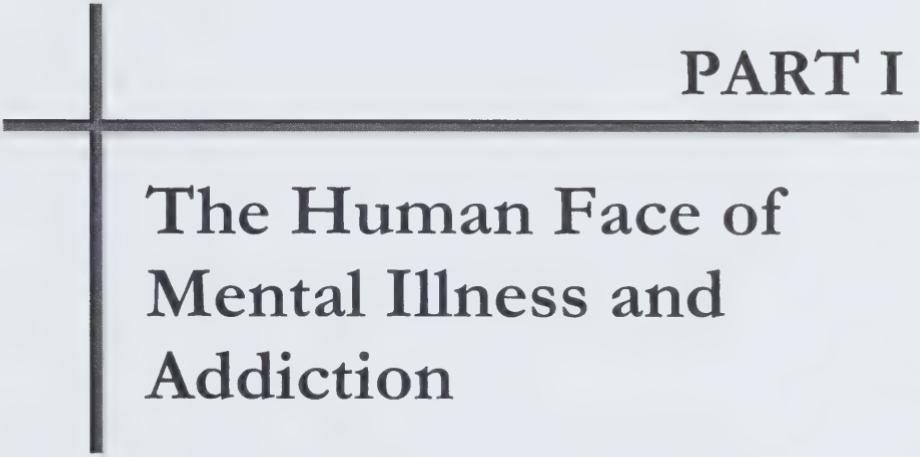
*To the people of Canada, I say welcome us into society as full partners. We are not to be feared or pitied. Remember, we are your mothers and fathers, sisters and brothers, your friends, co-workers and children. Join hands with us and travel together with us on our road to recovery.*

Roy Muisse — 9 May 2005 - Halifax<sup>2</sup>

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<sup>2</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).





**PART I**

**The Human Face of  
Mental Illness and  
Addiction**



## CHAPTER 1: VOICES OF PEOPLE LIVING WITH MENTAL ILLNESS

---



One of the most troubling stories heard by the Committee came from a young woman we had the opportunity to meet during our time in St. John's, Newfoundland. In tears, Helen Forristall told her story of being diagnosed with depression:

**The purpose of this chapter is to share with readers some of the stories we were told — in the words of those who told them. We hope that these stories will affect readers as they have every member of the Committee.**

*I do not like to admit it. I am ashamed and humiliated and I still have to work on that, but I am a mental illness consumer and I do take strong offence to stigma.*

[...]

*My doctor told me I had a sick brain just like somebody else would have a sick heart and that is fine and well in a doctor's office, but in society, that does not work. People tell me to, "Snap out of it," and "Think happy thoughts." They recommend books to you and they lay this guilt trip on me, such as, "You are too young to be depressed," and, "You have nothing to be depressed about..." Again, I did not choose this. If I had breast cancer, nobody would question me.*

*When I came to my employers and told them that I was depressed, they said, "Well, you will have to prove that." I said, "I intend to. I have a note from a psychiatrist that says so. If you would like to see my purse, I have lots of pills that I have to take and I have to suffer through."*

*I also have to suffer through the indignity of being looked down on and it bothers me a great deal, so it is difficult to sit here [at the public hearing]. I find myself hiding behind my hair when there is a picture being taken because I still deal with the shame every day.*

*I wanted to say that I left my job last year sobbing [...]. I worked with the federal government. I left my job, July 9. I have not been back. I am on the status of leave without pay, leave undetermined. I have to fill out questionnaires monthly to prove that I am still mentally ill.*

*I had to beg my GP to have an appointment with a psychiatrist. I begged him, I pleaded with him and his response was, "Yes, well, he has 600 active patients. He is getting old and you do not really need this. Just keep on taking your drugs..."*

[...]

*I am in a program in Merchant House for which I had to wait six months to get an interview to be accepted into the program. I am glad to say I am in the*

*program, but my counsellor has recommended that I go into group therapy, for which I am on two waiting lists. I am sixteenth on one list and she did not want to give me the number of the other list because it is much too long. She told me the program is supposed to last six months, but it ends up being two years or so because of the waiting lists.*

*[...] I have lost family and friends because they are afraid. The fear in this case is ignorance and I just have to deal every day with suicidal thoughts, medication, therapy and psychiatrists. It is not an easy road.*

*I would do anything to have breast cancer over mental illness. I would do anything because I [would] not have to put up with the stigma.<sup>3</sup>*  
— Helen Forristall

Helen's is a disheartening example of the lack of support from friends, family, co-workers and employers that many people living with mental illness face every day. Hers is also an example of the difficulty accessing mental health services all too often experienced by these individuals.

**I have lost family and friends because they are afraid. (...)**

**I would do anything to have breast cancer over mental illness. I would do anything because I [would] not have to put up with the stigma.**

**— Helen Forristall**

## 1.1 INTRODUCTION

Over the past year, the Standing Senate Committee on Social Affairs, Science and Technology has received more than two thousand submissions from all across Canada on the subject of mental health, mental illness and addiction. Hundreds of Canadians shared heartbreaking stories that revealed to the Committee the true state of Canada's mental health, mental illness and addiction "system."<sup>4</sup>

Through two online consultation processes, as well as hearings in every province and territory, the Committee heard from those who are most directly affected by Canada's mental health system, people who live or lived in the past with a mental illness or addiction. The purpose of this chapter is to share with readers some of the stories we were told — in the words of those who told them. We hope that these stories will affect readers as they have every member of the Committee.

The members of the Committee have come to recognize the reality that profound change is essential if persons living with mental illness are to receive the help they need and to which they are entitled. We trust that readers of this report will reach the same conclusion.

<sup>3</sup> 14 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>4</sup> As documented in the Committee's interim reports (November 2004), the extensive fragmentation of the delivery of mental health supports and services in Canada precludes speaking in any meaningful sense of a coherent and integrated mental health system. Throughout this report the term system is used simply to indicate that there is a multiplicity of types of services and supports, both formal and informal, available to people living with mental illness and addiction, no matter how insufficient they may be.

## 1.2 EXPERIENCES WITH MENTAL HEALTH AND ADDICTION SERVICES

Although the Committee did hear from people who managed to find the supports and services they needed, their stories, sadly, were far outnumbered by those from others about their ongoing struggles to get the help they need to cope with and recover from their mental illnesses and addictions. The Committee heard about the enormous challenges that they face and the tremendous barriers that hinder their efforts to recover: their confusion and frustration over how and where to find help; ignorance, lack of compassion, and poor treatment from health care professionals; long wait times for service; and the stigma and discrimination that make so many affected individuals hide their problems and often even avoid seeking help in dealing with them.

### 1.2.1 Confusion and Frustration

Tom, Paul, and James illustrate the frustration too many people experience in finding the assistance they need:

*I wanted to call for help. I had no food, was very cold. I was truly destitute. In calling the local addiction service I got an answering machine repeatedly. I had no phone number to leave. I hung up the phone and cried and cried. After that I became utterly homeless, was in jail and attempted suicide. What if someone was able to answer that phone?*  
—Tom

**I no longer have any hope or expectation that I will recover, nor do I feel that the government will ever provide me with any kind of meaningful treatment to help me overcome this illness.**

(...)

**So by giving up all hope I never find myself forced deeper into depression by a rejection and the quashing of hope.**

—James

---

*It is nearly impossible to get a full picture of the support available and how I can access it. Much of the information is disjointed and difficult for a layperson to understand.* —Paul

---

*In short, I gave up all hope in life. I no longer have any hope or expectation that I will recover, nor do I feel that the government will ever provide me with any kind of meaningful treatment to help me overcome this illness.*

*I live in a single room, alone, where I live out my days. The only reason I haven't killed myself is to spare my parents the pain it would cause.*

*I have never turned down a treatment, not even experimental drugs which I have tested on a couple occasions. However, without an advocate or a willing psychiatrist, I'm in no condition to face the continual rejection by specialists who hear my story and feel they can't help me. So by giving up all hope I never*

*find myself forced deeper into depression by a rejection and the quashing of hope. —James*

### 1.2.2 Lack of Knowledge and Compassion

Among others, Deborah, Jennifer, and Rafe told the Committee about the lack of knowledge and compassion that they encountered within the health care professions:

*If you are working in the mental health system, you have to care. You have to show people respect and dignity. This is something that I find is still missing.*  
—Deborah Jackman<sup>5</sup>

**Can you imagine if a woman went in to see her doctor with a lump on her breast being told, “Sorry, madam, I do not do lumps, but I can get you in to see a specialist within six months to a year.” Yet, the equivalent of that happens regularly to people who have overcome the stigma attached to mental health and go to their doctor.**

**— Rafe Mair**

---

*To speak from my personal experience, being on a psychiatric ward was one of the most traumatic experiences of my life.*

*The things that happen on a psychiatric ward taken in any other context would be seen as devastating. People being locked in tiny rooms they cannot leave, tied to a bed and injected with chemicals against their will are clearly traumatic experiences. Being told that it is all right because they are in a hospital is really a departure from reality.* —Jennifer Chambers<sup>6</sup>

---

*Can you imagine if a woman went in to see her doctor with a lump on her breast being told, “Sorry, madam, I do not do lumps, but I can get you in to see a specialist within six months to a year.” Yet, the equivalent of that happens regularly to people who have overcome the stigma attached to mental health and go to their doctor.* —Rafe Mair<sup>7</sup>

### 1.2.3 Lack of Services

Many participants, including Pat, Francesca, Susan, and Raymond, told the Committee that, aside from being confusing and frustrating to access, many times services are simply not existent for those who have a mental illness:

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<sup>5</sup> 14 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>6</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>7</sup> 7 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/19evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/19evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*The only resources we have in any abundance, yet again, are expensive psychiatrists, occupational therapists, and nurses and social workers who are reduced to delivering pills and needles, effectively keeping discharged patients in chemical straightjackets for the comfort of the mainstream community.*

*If a client is depressed and upset because his life is so narrowly constricted, his medication is increased. If he is fearful of a landlord or unable to sleep in an overcrowded room, his medication is increased. If poverty leaves him hungry and restless, his medication is increased, and if he has enough remaining life inside his body to be angry, the dosages will ensure that that anger is forgotten. —Pat Capponi<sup>8</sup>*

**We should not be concerned with what is good for the staff; we should be concerned with how these patients will get better and ultimately end up going back to their lives.**  
—Francesca Allan

*Another huge problem in the hospital is that they are looking for ease of management. Like, it is easier when people are drugged, they are no trouble, and they are just staring at the wall, staring at the TV. That might be a good thing for the staff.*

*We should not be concerned with what is good for the staff; we should be concerned with how these patients will get better and ultimately end up going back to their lives. —Francesca Allan<sup>9</sup>*

*Statistics prove that medication alone is not as successful as a combination of both psychotherapy and medication. Other forms of therapy are not available to those of us on fixed income or incomes that do not allow for the sometimes high cost of therapy through psychologists, social workers and alternative therapists.*

[...]

*I am slowly making my way back to a state of mental health, but will not be able to do so without the assistance of a psychiatrist and a psychologist. Our provincial health plan covers the cost of psychiatric services, but does not cover the cost of psychological services. I must pay for this unassisted by any private*

<sup>8</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>9</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*medical plan. My family is surviving on one income... —Susan Kilbridge-Roper<sup>10</sup>*

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*...what people need sometimes is a safe and comfortable place, open at hours they want, accessible to their needs, and feeling, and having a feeling of community and sharing food, talking to one another, laughing together, and helping one another. Unfortunately, here in Ontario, that does not constitute billable hours, so we do not get the kind of financial support that we need, but it is just as valid and just as helpful. —Raymond Cheng<sup>11</sup>*

## 1.3 WHAT ARE INDIVIDUALS LIVING WITH MENTAL ILLNESS ASKING FOR?

### 1.3.1 The Social Determinants of Mental Health

People personally affected by mental illness identified for the Committee a number of services they believed necessary for them to cope with and recover from their disorders. Social supports such as employment assistance and adequate housing, education and research, and self-help and peer support are those that were considered most important.

**Our provincial health plan covers the cost of psychiatric services, but does not cover the cost of psychological services. I must pay for this unassisted by any private medical plan. My family is surviving on one income...**

**—Susan Kilbridge-Roper**

Witnesses like Diana and Raymond explained that the social determinants of mental health have been largely overlooked despite their importance in preventing and in treating mental illness:

There has been a complete lack of attention to the social determinants of health as they relate to people with mental health or addiction issues.

*[...] Good health implies participation, self-determination and good self-esteem. —Diana Capponi<sup>12</sup>*

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<sup>10</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>11</sup> 17 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>12</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*...Mental health is integrated with one's physical, social, spiritual and economic well-being. Hope for a future is truly realized if there are genuine expectations that inequities within society will be addressed.*

*My friends [...] have already eloquently spoken about what it feels like to have a job, a place to call your own, and a social network of friends. I hope you heed our collective call that individual recovery from mental health is impossible when struggling with the consequences of poverty alongside stigma and discrimination. —Raymond Cheng<sup>13</sup>*

### 1.3.2 Employment Assistance

Karen, Joan, and another participant who wished to remain anonymous explained the difficulty often met by people living with mental illness who are trying to find jobs:

**...Individual recovery from mental health is impossible when struggling with the consequences of poverty alongside stigma and discrimination.**  
—Raymond Cheng

*In my own case, because I had been so open about my illness, it took me a number of years to find decent, secure employment. I felt that people now saw me as a gamble. If I had survived cancer, diabetes or high cholesterol, I'm not sure I would have faced the same challenges. —Karen*

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*People are petrified to go off of their income assistance, because when they stop and think about it, in the real world if they were out working, they would have to make upwards of \$50,000 a year to be able to stay on their medication.*

*I know of one individual whose medication totals \$1,500 a month, and that in itself is shocking, not that the person is taking that medication at that expense, but the fact that they are caught between the rock and hard place. Yet, at the same time, they want to work, but know that their skills base does not allow them to make the money to be able to support their medication. —Joan Edwards-Karmazyn<sup>14</sup>*

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*The way the Ontario Disability Support Program is set up, discriminates against people with mental illness who want to work because if they earn more than \$160 a month ODSP is*

**People are petrified to go off of their income assistance, because (...) if they were out working, they would have to make upwards of \$50,000 a year to be able to stay on their medication.**

—Joan Edwards-Karmazyn

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<sup>13</sup> 17 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07eve.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07eve.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>14</sup> 14 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evaluation.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evaluation.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*clawed back, guaranteeing that they will always be below the poverty line.*  
—Anonymus

### 1.3.3 Safe and Adequate Housing

Katherine and Scott explained that individuals with a mental illness often also face difficulty in finding safe, adequate housing:

**Good luck finding adequate housing when they find out you have a mental illness.**

—Katherine

*Good luck finding adequate housing when they find out you have a mental illness.* —Katherine

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*There are sections of this city, and many others in Canada, filled with boarding homes, and in those boarding homes and group homes, you will find people who have little more in their lives than regular doses of medication. Many of them live with little meaning or purpose because Canadian society fails to recognize they have worth. Some struggle with poverty so grinding and housing so appalling, it would challenge the sanity of even the strongest among us.*  
—Scott Simmie<sup>15</sup>

### 1.3.4 Peer Support

Many witnesses identified peer support groups as one of the most important services needed on the road to recovery from mental illness. Susan, Joan, Jean-Pierre, an anonymous contributor, and Roy told the Committee about the importance of peer support:

**(...) I learned more from my peers than I did in the previous 12 years dealing with what I call the “formal mental health system”.**

**I learned by listening to how others kept themselves well and what they did to maintain their mental health. I tried some of their methods and some of them worked. (...) I have not taken any medication since then nor have I received any formal mental health treatment since the year 2000.**

—Jean-Pierre Galipeault

*The value of self-help and support groups in recovery has been very well documented. My own experience as both a member and a leader of one such group has given me an intimate knowledge of the benefits that can be derived from sharing the joys and sorrows that we as people with common problems face on a daily basis.* —Susan Kilbridge-Roper<sup>16</sup>

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*Why self-help? People involved with their peers within self-help groups take on a proactive approach towards managing their problems and finding solutions.*

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<sup>15</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>16</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*The focus is on wellness and not illness, on ability and not disability, on becoming at ease with one's limitations and not remaining diseased within one's limitations, on focusing on the beginning of the recovery process and not on remaining stagnant within one's misery. It is about gaining the energy to have choice once again and setting about to plant the seeds of choice to enable the consumer-survivor once more to feel alive. —Joan Edwards-Karmazyn<sup>17</sup>*

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*I received my diagnosis quite a few years ago and it is fair to say that many Canadians with a mental illness treat that illness with medication. I spent almost 12 years trying to find the right medication.*

*Perhaps I am a slow learner, but when I found a self-help group, the light bulb went on.*

*[...] I learned more from my peers than I did in the previous 12 years dealing with what I call the "formal mental health system".*

*I learned by listening to how others kept themselves well and what they did to maintain their mental health. I tried some of their methods and some of them worked. The group experience led me to develop a personal recovery plan and in 1996, I went off my psychiatric medication. I am not an advocate of this generally, but I decided on this course because of concerns about long-term side effects. I have not taken any medication since then nor have I received any formal mental health treatment since the year 2000. —Jean-Pierre Galipeault<sup>18</sup>*

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*We need some programs available for people to learn skills/tools to help them cope better with people, relationships, stress, anger, sadness etc. Support Groups should always be available to attend, even just having a drop in-group or something so people come when they want.*

*It really does help to be able to talk to people who understand what you're going through and won't judge you. They may have some suggestions that worked for them in similar situations in the past that you may want to try. It's imperative to have a safe place to be able to talk openly about how you feel. —Anonymous*

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<sup>17</sup> 14 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>18</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*I have been living with a mental illness for almost 30 years.*

[...]

*I first received psychiatric treatment in the 1970s [...] [I]n 1979, I was hospitalized for the first time with a “nervous breakdown,” or what we recognize today as depression. The experience, to say the least, was horrible. This was a time when it was very common for people with a mental illness to be extremely overmedicated.*

[...]

*I somehow made it through the 1980s. I lost my business, my marriage broke up, and I became a person that I really did not like, but I refused to admit that there was something wrong [...]*

*Then came the 1990s. I became very ill throughout most of that decade. I attempted suicide twice and came very close on numerous other occasions. I had many hospitalizations and was on many different medications over the years and even went through a series of shock treatments [...]*

*In hospital, I was treated with respect and kindness, but I could see how overworked everyone was. At this time, I educated myself on depression and was willing to try anything that was suggested in order to get well. Nothing seemed to work [...]*

*I learned through volunteer opportunities that I had a natural ability to talk with and listen to other mental health consumers, and we all seemed to benefit from that [...]*

*This was a dream that I never believed could happen. As I sit here before you today, I am living proof that dreams can come true. In 2001, I was offered a job at the Consumer Initiative Centre, a program of the Self-Help Connection, an organization built on the power of peer support. I was hired as a peer support worker. —Roy Muise<sup>19</sup>*

## 1.4 STIGMA AND DISCRIMINATION

The stories of stigma and discrimination recounted throughout this chapter have only scratched the surface in revealing the attitudes and unjust treatment experienced daily by those living with mental illness.

Many contributors pointed to instances in which they had personally experienced stigma and discrimination in every aspect of their lives solely because they had been diagnosed with a mental illness or lived with an addiction.

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<sup>19</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

### 1.4.1 Stigma and Discrimination in Housing

Linda's and Phillip's stories illustrate the difficulties individuals with a mental illness have in finding safe and adequate housing:

*No one really knows what it is like until they experience living in a dark, damp room with no windows, no refrigeration, no heat and no rights. At the time I felt fortunate just to have a roof over my head and a bed to sleep in. I paid \$550 a month for this, a cockroach-, a mouse-infested room with the bed springs that scratched my body.*

*The bed springs made it impossible for me to sleep so I changed mattresses only to find the new mattress loaded with bed bugs. As horrible as this picture may seem, it was actually worse than I could describe. I was suffering from severe depression and finding myself in and out of hospital repeatedly. I lived in places like this for a good part of my life.*

[...]

*When I first saw my one-bedroom apartment, I could not believe it was mine. I did not think that I deserved such a beautiful place. I actually thought it might have been a mistake and it would be taken away from me. I had windows, they opened and I could see out; oh, the light, the sun. I could smell the grass and hear the birds. I had my own bedroom, my own washroom. I have a full kitchen with a stove and a refrigerator. Now I am able to cook my own meals and I can entertain with pride.*

[...]

*My life has completely changed since I moved into my own apartment. It is not just an apartment. It is my home. I am now a productive member of society.*  
—Linda Chamberlain<sup>20</sup>

**My life has completely changed since I moved into my own apartment. It is not just an apartment. It is my home. I am now a productive member of society.**

— Linda Chamberlain

**The homeless and mentally ill also have a right to live wherever they want, like anybody else. Nobody has a right to prevent us from living in their neighbourhood.**

— Phillip Dufresne

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*In the process of advocating for more supportive housing, often we must fight NIMBYism, Not In My Backyard; the stigma of mental illness; and zoning bylaws that discriminate against supportive housing.*

*The homeless and mentally ill also have a right to live wherever they want, like anybody else. Nobody has a right to prevent us from living in their*

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<sup>20</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*neighbourhood. This is blatant discrimination and a flagrant violation of human rights.*

*How would anybody in this room like it if somebody came up to you and said, "We do not want you living in our neighbourhood"? It does not matter why they say it to you; it is wrong. People are not allowed to prevent Blacks, gays or Jews from living in their neighbourhood because it is considered a hate crime and they should not be allowed to do this to the homeless and mentally ill either.*

*Nobody is criticizing us because of anything we have done wrong. They are criticizing us out of fear and ignorance. —Phillip Dufresne<sup>21</sup>*

## 1.4.2 Stigma and Discrimination in the Health Care Professions

Lisa, Sheila, Anita and Jeannie describe stigma and discrimination of another kind — from health care professionals themselves. The Committee has always found it difficult to understand how some professionals to whom vulnerable people turn for help could so often treat them in such a shabby way:

*I felt condescended to, and belittled by many of the doctors I came across in the mental health system.*  
—Lisa

**The health care profession is not very comfortable with any one of its own having a mental disorder.**  
—Sheila Hayes Wallace

**In our community, the only way to get prompt psychiatric care is to attempt suicide or commit a crime. That, in itself, is a crime.**  
—Jeannie

*The health care profession is not very comfortable with any one of its own having a mental disorder. It is kind of a "not in my back yard" attitude. Once labelled as damaged, that worker should go "somewhere else," not remain in this workplace. —Sheila Hayes Wallace<sup>22</sup>*

*I have waited in an Emergency Room for as long as 6 hours, in a suicidal state, while others with physical ailments have proceeded ahead of me.*

*The person at the desk who filled out the necessary paper work was informed of my condition. Yet in spite of this I was made to wait as another incoming patient had physical signs of distress, blood, broken bone.*

*Another thing is when one finally gets in to talk to someone, it's usually the psychiatrist in training, he asks many questions then he gets in touch with the*

<sup>21</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>22</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*Dr. on call, then the Psychiatrist on call comes to see you and you are asked the same questions all over again. For a person with extreme anxiety this is very frustrating and is enough to put you over the edge at which time you now are treated as a violent patient. —Anita*

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*In our community, the only way to get prompt psychiatric care is to attempt suicide or commit a crime. That, in itself, is a crime. —Jeannie*

### 1.4.3 Stigma and Discrimination Upon Return to Work

Another form of discrimination faced by people diagnosed with a mental illness — said by many who spoke to the Committee to be prevalent in the insurance industry — applies to those seeking to enter or re-enter the workforce as part of their efforts at recovery.

**(A bank...) asked me to fill out a form, and of course one of the questions was, "Have you ever had a mental illness?" And once you tick "yes" in that box, you will be denied insurance at Canadian banks.**

**—Scott Simmie**

Many witnesses, like Scott and Darrell, told the Committee of the difficulty they experienced in trying to obtain life, disability, or medical insurance and in filing provincial workers' compensation claims:

*In my own instance, I was off on disability, finally getting back to work and was going to get an RRSP loan. I went to the bank, a bank I had dealt with for years, and they said they would be happy to give me a loan. I told them I would like to get some insurance on the loan, because I was just returning to work and was not sure how long I would be there. They asked me to fill out a form, and of course one of the questions was, "Have you ever had a mental illness?" And once you tick "yes" in that box, you will be denied insurance at Canadian banks. —Scott Simmie<sup>23</sup>*

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*...you are not allowed to overcome your illness or any depression that you might have had. If you have indeed seen a psychologist or a psychiatrist at one point in your life, that will be brought out in order to diminish the claim or the extent of the claim when establishing PTSD or chronic pain syndrome, as in my case.*

*This abuse is so extreme, and so heavy, that I have come to the conclusion that there is no way that it could be dealt with when it is done on purpose without*

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<sup>23</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*opening up the human rights portion of the Charter. We have no powers as individuals to access our Charter rights. We do not. —Darrell Powell<sup>24</sup>*

#### 1.4.4 Stigma and Discrimination in Society

Perhaps the most damaging effect attributed by witnesses to stigma and discrimination was that originating in the belittling, denigrating attitudes toward mental illness and those who suffer it that seem to pervade all levels of society. Scott, Francesca, Ruth, Diana, Patricia, Kim and an anonymous contributor are but a small sample of the individuals who shared with the Committee the injuries they have suffered from these attitudes:

*When I first began researching mental health in 1998, I went to the largest psychiatric hospital in Toronto, and on the grounds of that hospital there was a sign. The sign was supposed to say "Dogs must be kept on a leash." Someone had spray-painted out the word "Dogs" and had put in the word "Nuts." "Nuts must be kept on a leash." Every time I drove by that hospital for an interview, I checked to see if that sign was there. Patients would have seen it, doctors would have seen it, and the public would have seen it. Eight months after I began my research, someone had finally spray-painted out the offending word.*

**I was a counsellor, I was a substitute teacher, I was a daycare worker, I worked in a women's shelter, but once they labelled me "mentally ill" I lost all credibility.**

**—Ruth Johnson**

**Why do we who suffer with this debilitating disease have to suffer socially as well?**

**—Kim**

*Now, imagine a different scenario; picture a similar sign on the grounds of a synagogue. If the word "Dogs" had been replaced by "Jews," people would have been outraged. The police would likely have been called, the act would have been described, accurately, as a hate crime, and rest assured, the sign would have been gone the very next day. Yet, the sign at the hospital remained unaltered for all that time, and who knows how long it had been there before I first noticed it. —Scott Simmie<sup>25</sup>*

*I cannot tell you how profound an impact a psychiatric label makes on your life. I mean, I lost my job and I lost my means for getting another job because I had been in the hospital. —Francesca Allan<sup>26</sup>*

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<sup>24</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>25</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>26</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*I was a counsellor, I was a substitute teacher, I was a daycare worker, I worked in a women's shelter, but once they labelled me "mentally ill" I lost all credibility. —Ruth Johnson<sup>27</sup>*

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*Whenever someone comes out as having a mental health issue, whether it is an employer, a small business operator or a person on the street, immediately, there are no expectations of those people, and I am not exaggerating when I say that. Actually, there is a fear, quite frankly, that you might be violent. That is the number one fear, and that is perpetuated. —Diana Capponi<sup>28</sup>*

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*I have volunteered for almost 20 years now and the last three years I have been a member of the Board of Trustees of CAMH. Notwithstanding that long-term achievement and 33 years of a teaching career, when I meet people and I say that I am a recovering addict, there is a drop in credibility. It is visible. It is fine to be a trustee. It is fine to be a retired teacher. It is fine to be a grandmother, but if I say that I am a recovering addict, there is that drop in credibility. —Patricia Commins<sup>29</sup>*

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*Broken. Lonely. Hopeless. Ashamed. Rejected. Isolated. Afraid. Unsupported. Lost. Anxious. Disbelieved. Overwhelmed. Embarrassed. Dark. Pained. Desperate. Fading.*

*I'm a 31-year-old Canadian woman who has been fighting the disease of Depression since my late teenage years. The words above are words that come to my mind when I think of what it's like to live as a Canadian in Canada with Mental Illness.*

*It's pretty sad when you sit around wishing you had any (literally ANY) other disease other than a Mental Illness. There is so much shame, stigma and disbelief that accompany a diagnosis of a mental illness. It's the constant justification that you're actually sick. Why do we who suffer with this debilitating disease have to suffer socially as well? —Kim*

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<sup>27</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>28</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>29</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*I shouldn't feel shame or fear or failure because I have a mental disease (Bipolar disorder). I should be able to get help and support as any other person with a disorder or disease. I should not need to try to educate people who do not want to learn about the illness but still have the power to make decisions about my life. —Anonymous*

#### 1.4.5 Suggestions for Ending Stigma and Discrimination

Those who told the Committee about their experiences with stigma and discrimination also provided ideas for eliminating such attitudes and making society more accepting of those living with mental illness.

##### 1.4.5.1 Education and Awareness

Almost unanimously, participants agreed on the need for education about mental illness and those affected by it. Patricia and an anonymous participant talked about the need for education and how it would help to alleviate stigma and discrimination:

**Only by changing our perception, removing the social stigma and understanding more about mental illness can we as a society begin to improve the treatment and care provided to the people who suffer from a mental disorder.**

**— Anonymous**

*Only by changing our perception, removing the social stigma and understanding more about mental illness can we as a society begin to improve the treatment and care provided to the people who suffer from a mental disorder.*

*Changing our perception means opening the door of hope for thousands of Canadians. It will mean giving the issue a higher visibility among our elected officials and a greater priority when developing our policy initiatives. Fear of mental illness reduces resources and assistance to mental illness.*  
—Anonymous

*The benefits and rewards of recovery can be identified by gathering information directly from recovering clients who are willing to disclose. This is difficult. There are not so many people in Canada who are willing to do this but there are some. Let us find them.*

*Public figures and private citizens, people from all walks of life might be motivated to speak up and share their insights, or to provide them in written form. Many people regain their lives and go on to be fully participating members of society. How did they do it? What helped them the most? What do they have to offer? —Patricia Commins<sup>30</sup>*

<sup>30</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

#### 1.4.5.2 *Stigma and Discrimination in the Media*

Roman and an anonymous contributor were among the participants who suggested that the media would be the most effective means of spreading insightful information about mental illness:

*Film and television have used mental illness to add drama to their productions by suggesting the character may be, or is, suffering from an illness, regardless of whether or not the character's behaviour could be attributed to other causes, either emotional or physical. The industry must be alerted to the damage these actions are inflicting on the mentally ill, and the harm they are doing in stigmatizing persons with a mental illness. —Roman Marshall<sup>31</sup>*

*More media coverage on the reality of mental illness, as opposed to the sensationalism and stigmatism of it, would be beneficial. People need to be taught that people with mental illness are not homicidal maniacs, as depicted on TV, but are friends, neighbours, professionals, etc. —Anonymous*

#### 1.4.5.3 *Recognition of the Seriousness of Mental Illness*

Many participants also emphasized the importance of treating mental and physical illnesses with equal seriousness both within the medical community and in society more generally. Frank, Lisa, and Sheila, together with others quoted previously in this chapter, explained that mental illness is often treated differently and with much less urgency and importance than physical illness:

**Mental illness is a physical illness, not some disease that enters the minds of the weak or characterless. Like cancer, it can happen to anyone.**

**Let's start treating "mental" illness as what they are. Devastating diseases.**

**—Lisa**

*I have had occasion to sit in the Regina General Hospital emergency room with friends from my group. We have gone home in despair. Unfortunately we are not a high priority, and I do not know why. Maybe if we had blood coming out of the side of our heads we would become a priority.*

*I will be graphic and blunt about this: We are not important. We do not seem to be important to the health professionals. I do not want to sit in another emergency room because a friend has said, "I cannot keep on living; I need help." I take them there and we are told to sit down.*

*There is a little board that says the next non-priority patient will be seen in three to four hours. I do not want to see that again. This person needs a room, needs safety. They may not need medication or anything like that, but*

<sup>31</sup> 31 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*they need safety. They want to know that somebody cares, and an open emergency waiting room is not the place for them to be.*

*We are looking and asking for respect and dignity. —Frank Dyck<sup>32</sup>*

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*Start treating mental illness as a biological illness the same as any physical disease. When we say that someone is sick we don't say "physically ill" so why do we say "mentally ill"? Mental illness is a physical illness, not some disease that enters the minds of the weak or characterless. Like cancer, it can happen to anyone.*

*Let's start treating "mental" illnesses as what they are. Devastating diseases. —Lisa*

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*How many corporations and businesses resisted putting ramps and elevators in place? Well, the business community did not collapse and now it is possible for people in wheelchairs and those who are people who are hearing and visually impaired to work.*

*Well, you know what? Now we need the equivalent for people who have mental needs. We need our own "ramps," for want of a better word. —Sheila Hayes Wallace<sup>33</sup>*

## 1.5 CONCLUSION

Throughout the consultation process, the Committee heard time and time again about the hardships faced by people living with mental illness and addiction, as well as about the resilience they demonstrate. Amidst the expressions of frustration, loneliness, and abuse, there were compelling stories of courage, hope and triumph over adversity.

**When we do speak, please do not avoid us. What we have is not contagious.**  
— Sheila Hayes Wallace

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<sup>32</sup> 2 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>33</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

People with personal experience with mental illness or addiction have been full, contributing partners to this first-of-its-kind study. Without their courage to step forward and share their stories with the Committee, this report would not have been possible. The Committee is most grateful for their willingness to share their intense and often painful personal experiences in an effort to improve the mental health, mental illness and addiction services in Canada for themselves and for others.

*When we do speak, please do not avoid us. What we have is not contagious.*  
—Sheila Hayes Wallace<sup>34</sup>

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<sup>34</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).



## CHAPTER 2: VOICES OF FAMILY CAREGIVERS

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### 2.1 INTRODUCTION

*The worst is not being able to help because you aren't part of the solution.*  
—Darlene

Of the many submissions received by the Standing Senate Committee on Social Affairs, Science and Technology, a great number came from family members who provide unpaid, non-professional care to those living with mental illness and addiction. Like Darlene, many caregivers feel excluded, ignored by the mental health, mental illness and addiction system in Canada. Ironically, it is these same family members who often provide most of the care and support to people living with mental illness.

Families spoke to the Committee of their multiple frustrations: with the mental health system; with the effects that caring for a mentally ill individual have on families; and with securing what they need in order to provide the best possible care for their loved ones. Committee members were struck not only by the impact that mental illness can have on the life and health of caregivers, but also by the fact that the enormous efforts of caregivers often go unrecognized and unappreciated by professionals and others in the mental health system.

### 2.2 EXPERIENCES WITH MENTAL HEALTH AND ADDICTION SERVICES

Mary, Donna, Doris, Bonita, and Carolyn shared with the Committee the difficulties involved in struggling on behalf of a family member exposed to poor and delayed treatment by the mental health system; they told stories of their loved ones seeking help, only to be turned away or brushed off:

**In the end, just to sum up, the tragedy does not lie with the disability; that is not the tragedy. The tragedy is in the way society treats the child and the family that is dealing with the disability.**

—Donna Huffman

*When our son was 24, he killed himself. Just maybe, if he had gotten proper care and a psychiatrist who was truly interested in what was bothering him back then, maybe he would be with us today.* —Mary

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*Unfortunately, access to care is a daily struggle. All the services you get in terms of your child with a psychiatric illness are as a result of hard-fought, hard-won battles.*

[...]

*In the end, just to sum up, the tragedy does not lie with the disability; that is not the tragedy. The tragedy is in the way society treats the child and the family that is dealing with the disability.*

*We can handle Alex. So far, we have been able to do so with the limited amount of support that we have been able to get, and we are very appreciative for that limited support. What we cannot do is constantly fight to get every single service. —Donna Huffman<sup>35</sup>*

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*In September 1984 I received a phone call from my son's landlady in Toronto advising me he was in a hospital psych ward after attempting to fly out of the window of his upstairs apartment. I was convinced then that it was the worst day of my life but of course it was not. It was the beginning of a catastrophic rollercoaster ride, culminating nine years later with him being judged not guilty of a second degree murder charge on the grounds that he suffered from a mental disorder.*

*When he was informed of what he had done, he spent three days throwing himself against the walls of his jail cell in an agony of intense remorse. During that time and during his four-and-a-half years at the Forensic Psychiatric Institute in Port Coquitlam he never received any psychological counselling other than a few group counselling sessions initiated by the institute's very kindly pastor. —Doris Ray<sup>36</sup>*

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*I have taken my son into the emergency room in a manic state and, trust me; it is an awful thing to do. I mean, he is walking around telling people they are witches and grabbing the magazines out of their hands and scaring them and I am sitting there thinking oh, my God, what is he going to do.*

*I had to argue with the doctor about his condition. They tried to tell me that he is on drugs or he is this or that.*

*I said: "Look, I know what he is. I know he is mentally ill. He has records, can't you get them?" No, it was just too much trouble. You have to get into a major argument with these people. So something needs to change there, that is for sure. —Bonita Allen<sup>37</sup>*

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<sup>35</sup> 1 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evc-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>36</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>37</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*I speak as the mother of a young woman who died after eight years adrift with severe anorexia-bulimia in a medical system that basically ignored this most deadly of the mental illnesses.*

[...]

*Within the mainstream of the medical system, Danielle often faced hostility from her medical treatment providers. She was treated as if this was some kind of wilful teenage thing, some kind of bissy fit that she was having. Not true. [...] Every bite, every step was a genuine struggle for her.*

*In addition, she did not receive care for anything not deemed part of the problem. Her bones deteriorated to the point where she was off the chart, but she was not eligible for the bone medicines because they only went to 65-year-olds.*

*[...] She did not receive use of the air bed, although they brought one into her room in the hospital in the hour before she died to relieve the pain of the bones and the muscles which had all withered so that she had no range of motion.*

[...]

*One sarcastic nurse said to us, "Well, what exactly do you expect of us?" and I said, "I would like to find a cognitive behavioural therapist for Danielle and a psychiatrist who could work different medications until he found the right one for her severe suicidal impulses five days every month." The nurse looked at me and said, "You are being absolutely unrealistic."*

[...]

*Danielle was turned away three times at emergency rooms when she went there scared that she might act on these suicidal impulses, because she wanted to live. It was not an attention-getting thing. They laughed at her plans. [...] One time, five days later, she had a good plan and she overdosed. I found her.*

*When she was in Toronto for two years waiting for her turn that never came up, at our expense in a rented room, she would go to the hospital emergency and stay between the double doors, because there she could wait safely until the impulse passed. She knew it would pass, but she had to be safe until it did.*  
—Carolyn Mayeur<sup>38</sup>

**I speak as the mother of a young woman who died after eight years adrift with severe anorexia-bulimia in a medical system that basically ignored this most deadly of the mental illnesses.**

**—Carolyn Mayeur**

<sup>38</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Carol's was one of the few hopeful messages we heard:

*My experience with mental health services is a result of my older son Peter being diagnosed with schizophrenia when he was 19. Peter is now 45 and I count him as a sort of success story, given the seriousness of his condition.*

*Since those days, Peter has been put on more modern medication. He has gained a university degree in Mathematics (it took 20 years); he works as a teaching assistant in [a university] math department [...]; he takes benefit from the Centre for the Disabled at that University; he continues his education with law courses; he works as a security guard sometimes; he volunteers for many causes; he lives with a woman who also has schizophrenia; and he counsels and advises other people he knows who have this condition or some similar mental problem. —Carol*

### 2.2.1 Lack of Information

Heather and Donna communicated to the Committee their dissatisfaction with the confusion and lack of information about where to turn for help when a loved one needs it. Many family caregivers explained that the greatest difference between a mental illness and a physical illness is that, for the former, it is so much more difficult to find information and assistance:

**Trying to get help is a frustrating, lonely journey. Most people make many, many calls in an effort to get help. When you finally find something that looks hopeful, you get on a ten month waiting list... it is like showing up in emergency with a broken bone and being told, yes, it is really broken, so try and do what you can with it and we will see you in ten months.**

**—Heather Dowling**

*When your child breaks an arm or a leg, you know where to go. You know that when you go there, someone will help you. You go to the emergency department and the nurse sees you, the doctor comes, you have an x-ray, and either you are given a cast, or worst luck, you need surgery, but you get help.*

*[...] If you have an eating disorder, it is not like that. You do not know where to go. Your parents do not know where to go for help. Lots of doctors and nurses do not know what to do for you. Many of them blame you for being sick. But you are sick, really sick.*

*Trying to get help is a frustrating, lonely journey. Most people make many, many calls in an effort to get help. When you finally find something that looks hopeful, you get on a ten month waiting list... it is like showing up in emergency with a broken bone and being told, yes, it is really broken, so try and do what you can with it and we will see you in ten months.*

*[...] That seems a ludicrous example, no one would ever do that, nor should they. However, this is what happens with mental illness all the time, and somehow it is acceptable.*

*At age 11, my daughter's treatment and ours as a family would have been very different if she had cancer rather than an eating disorder. [...] The experience of having a child with a mental illness has all of the fear, doubt, searching for answers, trying to cope, stress, and emotional trauma as having a very physically ill child, without any of the supports that a serious physical illness receives.*

**(...) I often wish my son had been born blind instead, because people recognize that fact. They would take one look at my son and say, "Okay, we know what it is, we know what the problem is, we know the services that he needs," and it would be that, and I would not have to spend so much time advocating and begging for help.**

**— Donna Huffman**

*You feel very much alone, and left alone.* —Heather Dowling<sup>39</sup>

*I just know myself — and this sounds horrible — but I often wish my son had been born blind instead, because people recognize that fact. They would take one look at my son and say, "Okay, we know what it is, we know what the problem is, we know the services that he needs," and it would be that, and I would not have to spend so much time advocating and begging for help.*  
—Donna Huffman<sup>40</sup>

## 2.3 THE IMPACT ON FAMILIES

Family caregivers shared with the Committee numerous stories of the heavy toll on the family imposed by caring for a loved one living with mental illness or addiction, in particular the physical and emotional effects of attending to a relative living with mental illness and the lack of recognition and support for what they do.

**When you face the reality that there is basically no treatment that you can find for your child, it just becomes totally unbearable.**

**— Phyllis Grant-Parker**

### 2.3.1 Physical and Emotional Effects

Carolyn, Joyce, Sheila, Lembi, and Phyllis described some of the physical and emotional effects experienced by family caregivers:

*Actually, all three of us in our family have developed chronic illnesses because of the eight years of stress living with somebody who at the end of her life looked like she had been in a concentration camp, and the incredible, non-productive*

<sup>39</sup> 31 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>40</sup> 1 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evc-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*stress of trying to access medical care and being told that we were out of line.*  
—Carolyn Mayeur<sup>41</sup>

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*As a young person, that is what my daughter said. Why would she bother taking her drugs, if that is all they could offer her? It is a life on medication, with no friends, living on social assistance, no future. What was the point of living? I had to agree with her. I always thought that if it did end up that she did kill herself, I could forgive her, because she would be at peace.*  
—Jan House<sup>42</sup>

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*It is terrible to say, but if my daughter killed herself, I would understand. My daughter has said to me, "I do not know what there is for me when I am hearing these voices and I cannot do this and I cannot do that. Why am I here? I would be better off dead." We have had intellectual conversations at times where she has had insight and can be quite academic about it, and it is very hard to come up with a reason to live.* —Sheila Morrison<sup>43</sup>

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*...my husband must re-qualify [for the tax credit] each year. I cannot tell you how stressful that is for him. He has to go to the doctor and ensure that the form is filled out correctly so that there will not be any question about it. This is a hugely stressful annual event. It is stressful for him and, talking about contagion, it is stressful for me. It is as though I take on that kind of stress too, because over the year, there is so much stress in coping with his stress that I cannot draw the line as to where his problem ends and mine begins. His problem is eventually my problem.* —Lembi Buchanan<sup>44</sup>

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*When you watch the impact on your child of a psychotic break and you learn that he or she has a serious mental illness, one that they are going to have to learn to manage for the rest of their lives, it is devastating as a parent, absolutely devastating. When you face the reality that there is basically no*

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<sup>41</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>42</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>43</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>44</sup> 5 July 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*treatment that you can find for your child, it just becomes totally unbearable.*  
—Phyllis Grant-Parker<sup>45</sup>

By contrast, Mark spoke about the positive impact that finding effective services for a loved one can have on a family:

*After the last 15 years, my son Kenny, who suffers from severe obsessive-compulsive disorder, now fits into the community after years of family disruption, in and out of hospitals, from one psychiatrist to another, and searching in vain for direction. Because of his compulsive disorder, we are constantly at odds with no cooperation from Kenny. He was living on the streets, with the constant anguish and panic of not knowing where he was; was he safe? At times he would show up in my studio, a street person, my son.*

*In our desperate search, we finally were able to connect my son into the system providing mental health services of supportive housing. [...] No words can express the feelings and relief a parent has to have their son or daughter function normally and enjoy life connected to community and especially family. We take comfort in knowing that when we pass on, our child will always have a safe, secure, affordable home.* —Mark Shapiro<sup>46</sup>

### 2.3.2 Lack of Recognition and Support for Caregivers

Even though family caregivers spend endless hours searching tirelessly for services and treatments and advocating on behalf of their loved ones, their efforts are often unappreciated or ignored. Joyce, Betty, Mike and two anonymous contributors shared their frustration with the lack of recognition and support for family caregivers:

**I will say this much: If families are not at the centre of developing services for families, they will not work. We are pretty tired of providing the services, doing the work and being ignored.**

— Betty Miller

**Many people in the mental health field don't appreciate the value that family members can be in the recovery process.**

— Mike

*...as a caregiver, you are in jail as well, because you are afraid to go anywhere for fear that you are going to miss a call — and you do not have the trust that you need to have in the system. Very often, we have felt very hopeless, very abandoned and ignored. I think that really does need to change.* —Joyce Taylor<sup>47</sup>

<sup>45</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>46</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>47</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*Please, as we shift our paradigm to put clients truly in the centre, remember who has been providing the bulk of mental health care and addiction care. We have, we the families and the friends, to the tune of billions of hours of “informal” care each year, and many billions of dollars saved in the system. Just take this as meaning that families are unsupported, unpaid, and ignored.*

*[...]*

*Ask families what they need and they will tell you. Ask us to help develop a service delivery system. We will. We know the system and we know what works and what does not. We have great ideas.*

*I will say this much: If families are not at the centre of developing services for families, they will not work. We are pretty tired of providing the services, doing the work and being ignored. —Betty Miller<sup>48</sup>*

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*Many people in the mental health field don't appreciate the value that family members can be in the recovery process. —Mike*

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*Many family members are the sole support services of the mentally ill while trying to provide support to other aging family members and working full-time jobs. The support systems to assist family members are non-existent. Special efforts must be made to reach family members of the mentally ill. —Anonymous*

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*Families play a vital role in the recovery of a consumer. A majority of families live with the consumer 24/7 and so have a unique knowledge of the family member who has the mental health problem. Families provide housing, social, financial support, help in navigating the system etc., and in essence are the first line of support.*

*They have a unique role in the system — a support to the consumer and at the same time because of their knowledge can work with professionals. This role must be recognized and families integrated not only at the support level but in the policy and implementation levels as well. —Anonymous*

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<sup>48</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

## 2.4 WHAT ARE FAMILY CAREGIVERS ASKING FOR?

Because families often provide a great amount of unpaid and unrecognized care and support, the Committee believes it is essential to listen carefully to their suggestions. Family members told the Committee of their need for a variety of things: better information and education; income support; peer support; respite; access to their family member's care plan and to be included respectfully by physicians and others in discussions of how and by whom that plan will be implemented.

### 2.4.1 Information and Education

Darlene and an anonymous contributor illustrated the need for more information and education about what their loved one is experiencing and how to help him or her:

*When 1 in 100 people has schizophrenia, is it too much to ask to have us all know what it is?*  
—Darlene

**My son was diagnosed with schizophrenia in 1997. He was sent home after only 3 days in hospital and I had no idea where to begin. No information was provided by the hospital; no follow-up phone call or meetings — merely the advice that our local MB Schizophrenia Society had material for me to read.**

— Anonymous

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*My son was diagnosed with schizophrenia in 1997. He was sent home after only 3 days in hospital and I had no idea where to begin. No information was provided by the hospital; no follow-up phone call or meetings — merely the advice that our local MB Schizophrenia Society had material for me to read.*  
—Anonymous

### 2.4.2 Income Support

Joan, Phyllis, Norrah and an anonymous contributor shared stories of the financial hardship that is often associated with caring for a relative living with mental illness to whom income supports are not available:

*We need to take into consideration the financial burden mental illness brings to families. Disability pensions for the mentally ill are ridiculously low and most families dig into their pockets to provide for basic needs such as new shoes, dental care, health care items and spending money.* —Joan Nazif<sup>49</sup>

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*...while we were very fortunate as a family to get access to this kind of support, it was at a tremendous family cost. It was a five hour drive from Ottawa for*

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<sup>49</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*us to see our son. The emotional impact of having him ill that far away was tremendous.*

*Over the 14 months we drove 49,000 kilometres, lost 50 per cent of our family income, closed a family business, and had \$29,000 worth of out-of-pocket expenses. —Phyllis Grant-Parker<sup>50</sup>*

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*Most of the families I know in this province are suffering beyond what you can conceive of. They are selling their homes, if they have them to sell.*

*I will speak of my own situation. I have nothing. I will remain in poverty for the rest of my life. [...] I will never own a home, a decent car. I may never even be able to hold down a decent job because of my son's disability. —Norrah Whitney<sup>51</sup>*

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*I have a child with autism/ADHD and several medical diagnoses. The simple fact is that if he needs surgery to save him, I can get it in 6 hrs or less.*

*I have no access to any treatment to help him be a productive member of society unless I fund all treatment myself. However, if I just choose to put him on drugs and let him sit in the corner, the province will willingly provide. —Anonymous*

**We need to take into consideration the financial burden mental illness brings to families. Disability pensions for the mentally ill are ridiculously low and most families dig into their pockets to provide for basic needs such as new shoes, dental care, health care items and spending money.**

**— Joan Nazif**

### 2.4.3 Peer Support

George described how important peer support is to family caregivers to share fears and frustrations and to learn coping skills from those with similar experiences:

*We try to convey to them that they are not alone on this journey; they have the love and support of all at the meeting to help them through their grief. I have seen people come to a meeting for the first time so devastated that they could not speak, and months later, I have seen the same people laugh for the first time without fear of guilt and shame. —George Tomie<sup>52</sup>*

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<sup>50</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>51</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>52</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

## 2.4.4 Respite

Betty and Annette discussed the importance of breaks, of respite care for family caregivers. Many contributors told the Committee how difficult it is to find trustworthy and knowledgeable caregivers whom they can comfortably leave in charge of their loved ones:

**Families are tired. We need help. We are getting old and we are afraid that our loved ones will be left to fend for themselves on the streets; and those streets exist in both rural and urban communities.**

— Betty Miller

*Families are tired. We need help. We are getting old and we are afraid that our loved ones will be left to fend for themselves on the streets; and those streets exist in both rural and urban communities.*

**Families need respite care; they need to be shown that not being able to care for someone isn't the same as not caring for someone; they need to feel that there is somewhere for them to go when they simply can't cope anymore.**

— Annette

*Families have legitimate fears and distinct needs of our own. [...] Maybe all we needed was an hour or so of someone helping us figure out our options. Understand that we are a little fatigued, we need a break. Maybe someone can take over for us for a while, give us some respite.* —Betty Miller<sup>53</sup>

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*Families need respite care; they need to be shown that not being able to care for someone isn't the same as not caring for someone; they need to feel that there is somewhere for them to go when they simply can't cope anymore.*  
—Annette

## 2.4.5 Providing and Accessing Personal Health Information

A great number of respondents stressed that access to information about their loved one's care and treatment was one aspect, perhaps the most important, of providing the best care possible for a family member suffering from a mental illness and/or addiction.

**Any mental illness extracts a terrible toll on family members. Family members require information, education, and support. Only when absolutely necessary for the sake of the client should family members be excluded from the treatment process.**

— Ruth Minaker

Brenda, Ruth, Phyllis, and an anonymous respondent spoke of the helplessness they felt as a result of being denied access to information about the care and treatment of their loved one. To compound their frustration, information pertinent to their loved one's care that they wanted to share with health care professionals was often dismissed or refused. Their exclusion is exacerbated by the application of laws that are intended to protect the rights of

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<sup>53</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

the individual but, in some cases of mental illness, increase the risk of serious harm to that individual and others:

*I have a 25 year old son who has been diagnosed with paranoid schizophrenia. He would go on the medication, then feel he was cured, stop the medication and his symptoms would get worse.*

*Because of the laws he could not be forced to stay on his medication and would eventually go back into the hospital on a form, in which an advocate would go in and ask him if he wanted to be there and of course he would say no.*

*He is now 25 years old, the voices in his head have become unstoppable and louder for him. His delusions have become increasingly violent and he has such beliefs that he can live forever if he drinks human blood (because God said, drink my blood) and that if he dies he will rise again. I assure you that I and my family, his probation officer, and his two psychiatrists have no doubt that if our son is not treated medically for his illness that he will eventually kill either himself or someone else.*

*He self medicates himself with drugs, as is common with this illness, to stop the 20 screaming voices in his head.*

*As a parent I am unable to help my son who so desperately deserves treatment because HE is the only one who can make this decision. All doors are locked to the people who love him the most. His family. We have to stand by and watch him disappear into someone we don't know and who we all now fear for our lives.*

*Yes... this is our worst life experience. Dealing with the law taking the rights away so that we cannot help our loved one.*

*I think if a loved one proves time and time again, and in our case when his doctors say he is a danger to himself and others, and cannot function without help, that a loved one of the mentally ill person should be able to step in and be his voice to make him take his medication and to make sure his medical needs are taken care of.*

*Currently our son is back in jail for threatening our lives. Do we think he will follow through with these plans? Yes we think so, so do his doctors, so does his probation officer, so do the police. You have to remember that when a paranoid schizophrenic is off his medication he doesn't see family, friends as who they really are but in his delusional mind they are people that are trying to kill him.*

*My son deserves to be treated for his mental illness. But as the law stands now at this point they will wait for him to carry out his threats, and he will, and then all will suddenly stand up and say wow, why didn't we see this coming.*

*So my simple answer to what could help make things easier on family members is simply to allow the family to help their loved one get better. Untie our hands and bear our pleas, give us back our loved one.*

*Is it not enough that they are sick? Do we have to punish them for being sick?*

*My biggest concern is that as a parent to a young man that we love so much, we cannot help him. That we have to watch him get worse and worse every day. We have to watch him being hurled into a justice system that he has no understanding of what wrong he did. He did what the voices told him to do, he did things out of desperation, he was hungry he needed food, he was scared, he was fighting for his life. Kill or be killed.*

*We know that when he calls us mom and dad he knows who we are, his parents. But when he refers to us by our first names we know that he thinks of us as his enemies. We have lived with locks on our bedroom doors for a few years now. —Brenda Valcheff*

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*Any mental illness extracts a terrible toll on family members. Family members require information, education, and support. Only when absolutely necessary for the sake of the client should family members be excluded from the treatment process.*

*[...] Long after the treatment team has delivered its services, in most cases the family will still be involved in the life of the client. —Ruth Minaker<sup>54</sup>*

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*I think it is essential that families be involved because we hold the benchmark of our family member. We know the person before their illness, and this illness can, during the early treatment time, seriously change behaviours. The medical team only sees the sick person.*

*Hence, we hold the benchmark, because true recovery is really to return a person to him or herself, to come back to who they were as close as possible. Therefore, parents and families need to be welcomed as part of the team... —Phyllis Grant-Parker<sup>55</sup>*

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*I have a son with a mental illness. He is an adult, nearly 40 years old. We have had to take care of him, have had suicide watch a number of times, taken*

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<sup>54</sup> 31 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>55</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*him to emergency numerous times, made sure he got to appointments, supported him emotionally, physically, financially and yet when it comes to input in his psychiatric care we are not even considered.*

*Our son can spout off lies to his Dr. and there is no way we can have input because he is an adult. Dr.'s need to talk to families or caretakers to ensure that the information they are getting from the consumer is accurate.*  
—Anonymous

## 2.5 CONCLUSION

Family members who provide care and support to relatives living with mental illness and addiction face a two-fold challenge. First, they must suffer with their loved ones through their daily hardships and use their limited personal resources to try to alleviate them. Second, they must contend with a mental health system that often excludes them from involvement in the information-gathering and decision-making processes while simultaneously leaving them to serve as the fail-safe mechanism to provide unlimited, unpaid care, filling in the cracks that open when any part of the so-called system fails.

**Do the people in public office need to lose a child to understand how desperate the situation of mental health is in Canada? Unfortunately it seems the only people who really care about this are those who have experienced it first hand.**

— Ginny

Family members who provide care and support to relatives living with mental illness have their own unique perspective on the mental health system and its reform. They have shown the Committee that despite their frustration and fatigue, they will continue to search for assistance for their loved ones and to provide it themselves when they come up empty-handed. The Committee acknowledges the contribution to this study made by these individuals. Their stories are valid; their voices must be heard; their recommendations must be acted upon.

*Do the people in public office need to lose a child to understand how desperate the situation of mental health is in Canada? Unfortunately it seems the only people who really care about this are those who have experienced it first hand.*  
—Ginny



## PART II

### Overview



## CHAPTER 3: VISION AND PRINCIPLES

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*Given that a model tends to shape our perception of circumstances, it substantially influences how and what services we seek to construct, be they in mental health or in physical health.<sup>56</sup>*

After two and a half years of studying the mental health and addiction “system” in Canada, it is still striking to the Committee how many key questions about that system cannot be easily answered. They range from factual matters (e.g., how much is spent annually in each jurisdiction on mental health services and supports?) to fundamental philosophical, medical and scientific issues relating to the nature of mental illnesses.

The Committee has heard many different points of view on the whole range of questions, all argued with passion, integrity and eloquence. The previous two chapters bear witness to the richness of this testimony.

In recent years, much progress has been made in developing new medications and new treatment methods for many mental illnesses. As well, people living with mental illness and their families have increasingly been making their voices heard and have rightly insisted on actively participating in making the decisions that affect them. Still, there is a very long way to go. This is why, in the background reports released in November 2004, the Committee clearly affirmed that maintenance of the status quo with regard to mental health, mental illness and addiction in Canada is not an acceptable option.

In the Committee’s view, what is needed is a genuine system that puts people living with mental illness at its centre, with a clear focus on their ability to recover. This chapter explains what the Committee means by recovery and lays the foundation for what follows in the report.

### 3.1 INTRODUCTION

#### 3.1.1 The Limitations of this Report With Regard to Substance Use Issues

The Committee believes it is necessary at the outset to acknowledge something that will become quickly evident to the reader of this report. The Committee has not been able to devote as much attention to substance use issues as it intended when it embarked on its study of “mental health, mental illness and addiction.” This report therefore focuses primarily on mental health issues.

There are, of course, many areas of overlap between mental health and substance use issues, not least of which involve people living with both mental health and substance use disorders. It is quite common for people to suffer from both. Research has shown that 30% of people diagnosed with a mental illness will also have a substance use disorder in their lifetime and

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<sup>56</sup> Anonymous participant, second e-consultation.

37% of people with an alcohol use disorder (53% who have a drug use disorder other than alcohol) also live with a mental illness.<sup>57</sup>

The relationship between services for mental illness (such as treatment for depression, anxiety disorders and schizophrenic disorders) and services for substance use disorders (including treatment for problematic alcohol use, withdrawal management services, methadone maintenance for opiate addiction and needle exchange programs) has been the subject of much discussion and debate across Canada. In previous decades, services for the two types of disorder were administered separately; they developed divergent treatment philosophies, used different terminology and constituted different ‘cultures’ that were often in conflict.

The ‘culture clash’ between mental health services and addiction services has created substantial problems for clients, particularly those with concurrent disorders. As a result of conflicting approaches to treatment, clients have often received confusing and inconsistent information and advice. It has been common for them to be excluded from mental health services if they admitted to substance use problems. Similarly, clients were often excluded from addiction treatment programs if they admitted to the use of antidepressant medications.

Because of the importance of substance use issues in general, and of this overlap in particular, the Committee has devoted a Chapter of this report to substance use issues, and has attempted to address areas of common concern at various points throughout the report. Moreover, there is an important recommendation in Chapter 16 that the federal government inject an additional \$50 million per year in concurrent disorder programs.

Despite this, however, the Committee is acutely aware of the limitations of this report with respect to substance use issues. This report only scratches the surface of many substance use issues that deserve a much fuller treatment. There are also many places where the Committee has been unable to examine fully the similarities and differences in approach in the mental health and substance use fields. It would clearly not be appropriate for the Committee to assume that conclusions it has reached after carefully considering the mental health evidence necessarily apply with respect to substance use issues. Some may apply, but the Committee has attempted to avoid any unwarranted assumptions in this regard.

### 3.1.2 Some questions of “language”

The language used to speak about an issue, and the models employed to understand it, have a significant bearing on the kinds of policy proposals favoured or endorsed subsequently. Nowhere does this ring more true than with respect to mental health, mental illness and addiction.

**The language used to speak about an issue, and the models employed to understand it, have a significant bearing on the kinds of policy proposals favoured or endorsed subsequently.**

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<sup>57</sup> Skinner, W., O’Grady, C., Bartha, C., and Parker, C. (2004) Concurrent substance use and mental health disorders: An information guide. Toronto: Centre for Addiction and Mental Health.

This report is about mental health, mental illness and addiction. How, then, should this report refer to the people most directly affected by mental illnesses and addictions? As the Committee noted in its interim report, there is no single, easy choice:

Traditionally, individuals with mental illness and addiction being cared for by physicians are called patients. Other health professionals often refer to such individuals as *clients* or service users. The individuals may describe themselves by a number of terms, commonly consumers and survivors. Consumers usually refer to individuals with direct experience of significant mental health problems or mental illnesses who have used the resources available from the mental health system.

In its initial reports, the Committee chose to use the term “people living with mental illness” as its broadest reference. It also used the term “patient/client” where relevant. It is important to clarify further how these various terms will be used throughout this report.

**In addition to “people living with mental illness” as a generic term, the Committee will also employ the phrase “people with direct experience of mental illness.”**

In addition to “people living with mental illness” as a generic term, the Committee will also employ the phrase “people with direct experience of mental illness.” Other terms will be used as appropriate. The term “patient,” for example, can be used when referring to people who are actually receiving medical treatment. Used as a general term, however, it conveys an impression that is overly medical; the Committee heard repeatedly, and compellingly, that more than medicine is involved when dealing with mental illnesses.

**The Committee will use the word “consumer” to refer to people who are using available mental health supports and services. It will not be used, however, to refer to all those living with mental illness.**

An anonymous participant in the Committee’s second e-consultation put it this way:

*In making your final recommendations, I hope the Senate Committee will acknowledge that mental health care is more than psychiatry and clinic services. Though those things are extremely important, they can only be helpful as part of a broader community support system which adequately addresses the needs of mental health consumers. —Anonymous*

For her part, Jocelyn Green, Director of Stella Burry Community Services in St. John’s, pointed to the potentially beneficial impact of a broader approach:

*The formal mental health system is still too hierarchal and pathology-based. Yes, obviously, there are severe, legitimate mental illnesses that need treatment and medication, but I think we often fail to factor in the systemic roots of many mental health problems, such as poverty, abuse, discrimination, the lack of child care and affordable housing. I think if a lot of those issues were*

*addressed, certainly a lot of the people that are coming through our formal systems would not need to be there. —Jocelyn Green<sup>58</sup>*

The term “consumer” poses similar difficulties. The Committee will use it to refer to people who are using available mental health supports and services. It will not be used, however, to refer to all those living with mental illness. One reason is that the majority of those with a mental disorder or substance use disorder, as shown in a recent national survey conducted by Statistics Canada,<sup>59</sup> do not access mental health services or supports. Clearly, calling *all* people living with mental illness “consumers” is inaccurate; the same limitation applies to the term “client.”

The Committee is also sensitive to the fact that the term “consumer” has a variety of meanings and is not liked by many to whom the designation might apply. As one respondent to the Committee’s e-consultation wrote:

*I do not like the word “Consumer” — I find that stigmatizing. Other people who have illnesses are not defined in this manner. It gives the impression that because of our illness we overuse services. The word makes me think of a fire consuming that which sustains it. It has a very negative connotation and I think it should be dropped. People with personal experience with mental illness is quite adequate... just like people with personal experience with cancer or any other number of known diseases. —Anonymous*

Others pointed to the many commercial overtones of the term. For all these reasons, the Committee believes that it is not the best term to use to refer in the broadest way to all those who are living with mental illnesses. In this report, therefore, the Committee will use the term consumer only to refer to those who are in fact using available mental health supports and services, or when speaking about groups and individuals who refer to themselves as consumers.

### 3.1.3 The Mental and Physical Dimensions of Illness

People living with mental illness and addiction have faced, and continue to face, stigma and many forms of discrimination that compound the effects of their illnesses. As the Committee previously noted, this systematic discrimination is one explanation for the fact that mental illness, in general, is not often treated with the same degree of seriousness as physical illness.<sup>60</sup> This situation must be redressed.

**People living with mental illness and addiction have faced, and continue to face, stigma and many forms of discrimination that compound the effects of their illnesses.**

The Committee senses that there is, in fact, a broad consensus in favour of equity of treatment among Canadians. Most would agree that having providers and others treat mental

<sup>58</sup> 15 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>59</sup> Statistics Canada (2003) Canadian Community Health Survey, Cycle 1.2, Mental health and Well-Being.

<sup>60</sup> See Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1—Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Ch. 3.

illness with the same seriousness as physical illness is part of the fundamental entitlement of people living with mental illness to the same rights and privileges as all other Canadians. Achieving equity of treatment would mark an important step in combating the stigma associated with mental illness and addiction and the discrimination against people living with them.

But it is important to clarify what “treating mental illness like physical illness” really means. There is nothing approaching universal agreement on how mental and physical factors influence the state of our mental health. Indeed, there are many different ways in which social, environmental, psychological, and biological factors are thought to interact in the development of mental disorders, although most people seem to agree that mental illnesses almost always entail some combination of these factors.

However, different emphases placed on the role of these four factors can and do lead to very different approaches to mental health policy. For example, someone who believes that the key to “curing” mental illness is an understanding of the underlying functions of the brain, would be much more likely to support spending scarce research dollars on neurophysiology than on studies of the impact on individuals of the social determinants of mental health.

**(...) the Committee believes it is extremely important to stress the significance of what are called the social determinants of health in understanding mental illness and in fostering recovery from it.**

In the Committee’s view, it is essential to recognize that in treating mental illness comparably to physical illness it is not necessary to treat them as if they were identical to one another. Mental and physical illness are both like and unlike each other. There are key similarities and key differences, many points of overlap, but also features that are unique to each.

In particular, the Committee believes it is extremely important to stress the significance of what are called the social determinants of health in understanding mental illness and in fostering recovery from it. The Committee was repeatedly told that factors such as income, access to adequate housing and employment, and participation in a social network of family and friends, play a much greater role in promoting mental health and recovery from mental illness than is the case with physical illness. As well, it is important to see that the direction of causality goes both ways, from the mental (psychological, emotional, etc.) to the physical (neurobiological) as well as from the physical to the mental.

**What the Committee means, then, by treating mental illness like physical illness is best understood to mean that both types of illness must be treated with equal seriousness, by providers, by all Canadians — and particularly by governments.**

What the Committee means, then, by treating mental illness like physical illness is best understood to mean that both types of illness must be treated with equal seriousness, by providers, by all Canadians — and particularly by governments. People who are living with mental illness and addiction must be accorded respect and consideration equal to those given to people affected by physical illnesses. The Committee has sought to make this one of the guiding principles that underpin this entire report.

## 3.2 RECOVERY

This report focuses on facilitating the recovery of people living with mental illness and addiction. Widely documented in the field of addictions, the idea of recovery has been applied only relatively recently (over the past decade) to mental illness. The goal of recovery for people living with mental illness has nonetheless gained considerable acceptance in that time.

**The Committee believes that recovery must be placed at the centre of mental health reform.**

The Committee noted previously that:

*Recovery* is not the same thing as being cured. For many individuals, it is a way of living a satisfying, hopeful, and productive life even with limitations caused by the illness; for others, recovery means the reduction or complete remission of symptoms related to mental illness.<sup>61</sup>

The Committee believes that recovery must be placed at the centre of mental health reform. Studies have shown that even people with the most severe mental illnesses who have been decades under institutional care, can and do recover.<sup>62</sup> Long-term studies of the impact of serious mental illness have demonstrated that a significant number of affected people are able to regain full function.<sup>63</sup> Research carried out by the National Empowerment Centre, based on in-depth interviews with people diagnosed with schizophrenia, bipolar or schizoaffective disorders, confirms the capacity for recovery.<sup>64</sup>

**The Committee is aware that not everyone living with a mental illness will be able to recover, but, (...) believes recovery to be the primary goal around which the mental health delivery system should be organized**

Although the term recovery also has a number of drawbacks, the Committee nonetheless believes it is the most appropriate one for all the reasons outlined in this section. The Committee is aware that not everyone living with a mental illness will be able to recover, but,

<sup>61</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1—Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada,, Ch. 4, p. 79.

<sup>62</sup> Harding, C. (1987) The Vermont Longitudinal Study of Persons With Severe Mental Illness, II. American Journal of Psychiatry, Vol. 144, pp. 727-735.

<sup>63</sup> Moran, M. (2004) Schizophrenia Treatment Should Focus on Recovery, Not Just Symptoms. Psychiatric News (American Psychiatric Association), Vol. 39, No. 22. Also Jacobson, N., and Curtis, L. (2000) Recovery as Policy in Mental Health Services: Strategies emerging from the States. Psychiatric Rehabilitation Journal, Vol. 23, No. 4.

<sup>64</sup> Fisher, D., and Ahern, L. (1999) People can recover from mental illness. National Empowerment Centre, [http://www.power2u.org/recovery/people\\_can.html](http://www.power2u.org/recovery/people_can.html). It is interesting to note in this context the results of World Health Organization studies conducted in 1979 and 1992 that looked at recovery rates from schizophrenia in developing compared to industrialized states. Using matched controls, they found recovery rates in developing countries were twice those of industrialized nations. Some commentators have speculated that the more social approach of the developing countries worked to keep people connected to their communities and assisted in their recovery.

as explained below, it believes recovery to be the primary goal around which the mental health delivery system should be organized.<sup>65</sup>

Advocacy groups have been central in promoting the focus on recovery. In this regard, a participant in the Committee's e-consultations commented:

*Surprisingly when considering the history of psychiatric treatment recovery can be seen as a radical concept. The demand to see the human potential of consumers and the expectation that help will lead to recovery was spawned by the consumer and family movement. —Anonymous*

Kim Baldwin, Director of Mental Health and Addictions Services for the St. John's region, also noted that:

*"Recovery" is a term we have used in the addictions field for a long time and have been getting to know it in terms of mental health as well. It is a concentration on wellness as opposed to focusing on the illness.*<sup>66</sup>

Numerous witnesses testified about the significance of this shift of focus, including Jean-Pierre Galipeault, owner of the Empowerment Connection in Dartmouth, Nova Scotia, who gave the Committee a sense of the far-reaching implications of adopting a recovery framework:

*There are different definitions of recovery, but my business, The Empowerment Connection, defines recovery as, "[o]ccurring when a person's psychiatric diagnosis or emotional and psychological trauma is no longer the central focus in that person's life, but simply becomes a part of who that person is." We must remember that people also have to face the task of recovering from the effects of external and internalized stigma, learned helplessness, institutionalization, poverty, homelessness and the wounds of a broken spirit.*<sup>67</sup>

The histories of people diagnosed with a mental illness are extremely varied; a wide variety of treatments, services and supports can assist recovery. For most consumers of mental health services it is their family physician who is the first, and often only, port of call.<sup>68</sup> Having access to psychiatrists, psychologists, nurses and other health professionals can also make an invaluable contribution to the well-being of people living with mental illness. At the

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<sup>65</sup> The Committee acknowledges that there is a wide-ranging debate surrounding the applicability of the term "recovery" to some disorders, particularly autism. The Committee heard from a number of passionate advocates for autistic people that recovery is not their goal, because they do not consider autism to be an illness from which recovery is necessary (see also Chapter 6 on Children and Youth for more discussion of issues relating to autism). This is not an issue that the Committee can decide. It will therefore use the term recovery in the way described in this chapter.

<sup>66</sup> 14 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>67</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>68</sup> Macfarlane D. (June 2005) Current state of collaborative mental health care, p. 5. Report prepared for the Canadian Collaborative Mental Health Initiative, Mississauga, Ontario. Available at: <http://www.ccmhi.ca>.

same time, witnesses also pointed to the need for other kinds of services and supports to be available, as Raymond Cheng (a consumer and peer advisor) noted:

*...what people need sometimes is a safe and comfortable place, open at hours they want, accessible to their needs, and having a feeling of community and sharing food, talking to one another, laughing together, and helping one another.<sup>69</sup>*

Recovery has increasingly been embraced within the broader mental health sector,<sup>70</sup> as well as in government circles. For example, as the Committee noted in its review of mental health policies and programs in other countries, the goal of fostering recovery was placed at the centre of a recent national mental health report in the United States.<sup>71</sup> In practical terms, one of the attractions of a recovery orientation is that it may help create a framework within which services can be meaningfully measured and evaluated.<sup>72</sup>

### 3.2.1 The Need for a Recovery-Oriented System

Two models of recovery have been developed: the Psychosocial Rehabilitation Model and the Empowerment Model. The first arose within the professional community, while the second has largely come from the consumer advocacy movement. Although the two models are similar

**Very broadly, recovery suggests that the goal of mental health policy should be to enable people to live the most satisfying, hopeful, and productive life consistent with the limitations caused by their illness.**

in some respects, there are also important differences. Often used interchangeably by planners, depending on how they are applied the philosophical differences between the models can result in the development of different approaches in service delivery. The two models are described in more detail in the appendix to this chapter.

Drawing on these two models,<sup>73</sup> the Committee has concluded that a policy approach based on the idea of recovery must acknowledge the following:

- Each person's path to recovery is unique;
- Recovery is a process, not an end point;
- Recovery is an active process, in which the individual takes responsibility for the outcome, with success depending primarily on collaboration among helping friends, family, the community, and professional supports.

<sup>69</sup> 17 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>70</sup> Provincial Forum of Mental Health Implementation Task Force Chairs. (December 2002) *The Time Is Now: Themes And Recommendations For Mental Health Reform In Ontario*. [http://www.health.gov.on.ca/english/providers/pub/mhitf/provincial\\_forum/provincial\\_forum.pdf](http://www.health.gov.on.ca/english/providers/pub/mhitf/provincial_forum/provincial_forum.pdf).

<sup>71</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 2 — *Mental Health, Mental Illness and Addiction: Mental Health Policies and Programs in Selected Countries*, Ch. 4, p. 71.

<sup>72</sup> Canadian Mental Health Association, Ontario Division. (March 2003) *Recovery Rediscovered*.

<sup>73</sup> See appendix to this chapter. Also Jacobson, N., and Curtis, L. (2000) *Recovery as Policy in Mental Health Services: Strategies emerging from the States*. *Psychiatric Rehabilitation Journal*, Vol. 23, No. 4.

Recovery is about hope. As we noted earlier, recovery does not necessarily equate with cure. It can mean different things to different people. Very broadly, it suggests that the goal of mental health policy should be to enable people to live the most satisfying, hopeful, and productive life consistent with the limitations caused by their illness. For some, recovery will equate to the reduction or complete remission of symptoms related to mental illness.

**Recovery allows us to define the role of the system: It is to facilitate the ability of people living with mental illness to deal actively with the limits imposed by their conditions.**

**A recovery-oriented system must rest upon three pillars: choice, community and integration.**

In the past, much of mental health planning has not focused sufficiently on the outcomes achieved by people using the services provided within the mental health system. Recovery provides a focus for re-orienting the design and delivery of mental health programs, services and supports. Importantly, it allows us to define the role of the system: it is to facilitate the ability of people living with mental illness to deal actively with the limits imposed by their conditions.

As Darrell Burnham, Executive Director of the Coast Mental Health Foundation, told the Committee:

*The path to recovery is not clearly drawn in a map. We see it as a very person-centred approach; that people will have their own way back into society. The system needs to foster that and facilitate that rather than deliver a specific program that may prejudice that path.<sup>74</sup>*

Working toward a recovery-focused system is a complex undertaking. It involves coordinated action by governments at all levels, and at each level there are multiple ministries, agencies or departments, each usually having only minimal awareness of what the others are doing. It involves tens of thousands of providers working both inside and outside the formal mental health care system, some paid within the public system and others not, as well as hundreds of thousands of unpaid caregivers, using whatever resources they can find to help their friends and loved ones, volunteering their time and energy when they can.

There is always the danger that the idea of recovery will be embraced rhetorically but not translated into policy and action.<sup>75</sup> In the next three sections of this chapter, a bridge is suggested between the notion of recovery and the specific proposals for reform contained in the remaining chapters of this report. In the Committee's view, a recovery-oriented system must rest upon three pillars:

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<sup>74</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>75</sup> In the broader health care field, one can think of the issue of primary care reform as offering a cautionary tale in this regard. For over a decade, every major report on the hospital and doctor system in Canada has pointed to the need for significant reform to the ways in which primary health care is delivered, but progress on the ground has been very slow.

- **Choice:** Access to a wide range of publicly funded services and supports that offer people living with mental illness the opportunity to choose those that will benefit them most;
- **Community:** Making these services and supports available in the communities where people live, and orienting them toward supporting people living in the community;
- **Integration:** Integrating all types of services and supports across the many levels of government and across both the public/private divide and the professional/non-professional dichotomy.

### 3.3 CHOICE

In general, the range of choices that have been available to consumers of mental health services has been severely limited. The system has lacked both the resource capacity and the flexibility to provide personalized services that engage individuals in their own recovery, whether they are seeking treatment in an acute inpatient ward or living in their communities.

**It is people living with mental illness themselves who should be, to the maximum extent possible, the final arbiters of the services that are made available within the overall mental health system and of the ways in which they are delivered.**

This is how Darrell Downton, Co-Chair of the Mental Health and Addictions Advisory Committee of the Five Hills Health Region in Saskatchewan, put it in his testimony to the Committee:

*The limited options available to people with mental illness and addictions confirm to them that they are not eligible to receive the care and support they deserve. Their recovery is limited by the options available.<sup>76</sup>*

Viewed from the perspective of fostering recovery, choice is both a means to an end — a more responsive service — and also an end in itself. This is because being able to make choices is a manifestation of the rights and responsibilities of adulthood, and of full citizenship. The availability and exercise of choice is itself a potential contributor to the recovery process.

**Current funding arrangements mean, therefore, that many services needed by people living with mental illness and addiction are available only to those who can pay for them out of their own pockets, or who have private insurance plans that cover them.**

The Committee believes that it is people living with mental illness themselves who should be, to the maximum extent possible, the final arbiters of the services that are made available within the overall mental health system and of the ways in which they are delivered. In this sense, it is legitimate to speak in terms of encouraging a consumer-driven, or consumer choice, approach.

<sup>76</sup> 2 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

This is the best way both to encourage the elaboration and implementation of practical solutions to the problems encountered by people living with mental illness and addiction, and to promote the mental well-being of the population as a whole. No single body, least of all a governmental one, should be so arrogant as to believe it can prescribe a universal treatment model for all people living with mental illnesses and addictions.

Furthermore, no single treatment model should be allowed to dominate the policy horizon, either in theory or in practice. Many people will find successful treatments or care that are derived from a purely “medical” model, while others will look to their particular community or cultural traditions for ways of achieving the best mental health possible.

Moreover, because of the complexity of mental illnesses and their intimate connection with each individual’s unique circumstances and environment, many will find that they will need to draw on treatments, supports and ways of caring that combine elements drawn from multiple approaches.

Allowing people a range of choices that can be based in a variety of traditions is not merely the expression of a philosophical preference — it has important national policy implications. It points to the need to address the fact that an institutionalized bias is built into the way public funding for health care services works in Canada: under the *Canada Health Act*, only services that are provided by physicians or in hospitals are *required* to be publicly funded.<sup>77</sup>

While other services may be funded by individual provinces or even at the community level, access to them will vary widely. Current funding arrangements mean, therefore, that many services needed by people living with mental illness and addiction are available only to those who can pay for them out of their own pockets, or who have private insurance plans that cover them.

The services provided by psychologists are one example that the Committee heard repeatedly. As one e-consultation respondent argued:

*The biomedical model does not address underlying issues like abuse. I believe the origin of my illness is from childhood incest. Childhood sexual abuse has devastating consequences to a person's life. A huge percentage of people diagnosed with Borderline Personality Disorder have suffered sexual abuse. I can not afford to pay a psychologist \$150 an hour to treat me. The most important thing I need is therapy. —Anonymous*

This was echoed by another respondent:

*Ever since the “revolution” in drug treatment for psychiatric disorders, psychiatrists have gradually dropped their role as psychotherapists. Psychotherapy is only covered by my provincial health plan if provided by a psychiatrist (as a medical doctor). I have taken far more medication than I*

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<sup>77</sup> See Standing Senate Committee on Social Affairs, Science and Technology. (October 2002) *The Health of Canadians — The Federal Role*, Volume Six: Recommendations for Reform, Ch. 17. Note that specialized psychiatric hospitals were explicitly excluded from the purview of the *Canada Health Act* because they were deemed to be long-term care facilities whose regulation was not the intent of the Act.

*would have liked at an exorbitant cost to my health and to my provincial health plan, when I could have done with much less medication and had a far quicker recovery had I been able to afford psychotherapy. If the provincial plan had paid for my psychotherapy I believe that they would have saved money and my overall mental and physical health would be better as a result.*  
—Anonymous

Providing people living with mental illness with access to a full range of services and supports in addition to those provided by physicians and hospitals, and enabling them to select freely the ones they prefer, requires that an adequate range of services be made available and that people have available the funds to pay for them.

The Committee is aware that creating the conditions to sustain an environment that allows people living with mental illness to choose those services that benefit them most will not be easy. There will always be hard policy decisions to be made about how public resources can best be used. Moreover, no one can expect that all options will ever be freely available for everyone who desires them.

On the one hand, this means that policy decisions about which services and supports should be widely available and accessible to those who would choose them must be made on the basis of the best available evidence as to their effectiveness. Given the multiple dimensions implicated in mental health issues (social, environmental, medical, biological), it is necessary to apply a methodological pluralism to the selection and evaluation of the evidence of effectiveness itself. Relevant findings derived from the medical sciences, social sciences, and from people with direct experience of mental illness must all count in weighing such evidence.

**Consumers of mental health services and supports (...) must be heard at the policy table, just as they should be allowed to make individual choices about which services and supports are right for them.**

On the other hand, the need to collectively set the priorities for public spending points to another dimension of fostering choice. Consumers of mental health services and supports must be given the opportunity to participate actively in the process of collective decision-making. Their collective voice must be heard at the policy table, just as they should be allowed to make individual choices about which services and supports are right for them.

### 3.4 COMMUNITY

An orientation to providing access to community-based services and supports is the second pillar needed to support the creation of a recovery-oriented system. The evidence is clear that the shift begun many years ago away from institutionalized models of care was the right one, even if it was not always sufficiently resourced in practice.

**An orientation to providing access to community-based services and supports is the second pillar needed to support the creation of a recovery-oriented system.**

Many witnesses stressed the importance of this community-based orientation:

*In all the literature I have read about recovery, every person who discloses on this topic says that connection to the recovery community is the most important fact of ongoing recovery. Otherwise, relapse is particularly inevitable — sending the person back into a poorly functioning state. —Patricia Commins<sup>78</sup>*

Others pointed to the range of resources required in the community to support and sustain the recovery process. Geoff Chaulk, Executive Director of the Newfoundland and Labrador division of the Canadian Mental Health Association, told the Committee:

*The community resource-based model with the person at the centre of the system also addresses the essential elements for successful community living and recovery, including adequate housing and income, work, social connections and mental health services and supports.<sup>79</sup>*

Since mental health and addiction problems cut across so many facets of community life, much more than health care and other publicly funded social services will be required to respond properly. A wide variety of forms of community action make meaningful contributions to people affected by mental illness and addiction; without them, publicly funded services would be left to struggle with an overwhelming challenge. In addition, by making the community the focus for service provision, people can stay close to their personal support networks.

**For people living with serious mental illness, there is strong evidence that with the proper supports in place they can not only live in the community but also lead fulfilling and productive lives.**

But Dr. Paul Garfinkel, CEO of the Centre for Addiction and Mental Health, cautioned that:

*...community care is not cheap care. Community care requires specialized resources with knowledgeable people who provide care and treatment. We have a treatment program for psychosis involving 100 people with schizophrenia. Our team goes out to the homes in Toronto and keeps these people at home, very successfully. It is an excellent treatment program. It involves 100 people who, for sure, would have been in hospital. However, it is expensive. You need a doctor. You need a nurse. You need a social worker. You need a whole team.<sup>80</sup>*

The significance of basing mental health services and supports in the community holds for people living with all types of mental illnesses, from the mildest to the most severe. But the mechanisms through which the needed services and supports are best delivered will vary according to the severity of people's illnesses as well as their individual capacities to cope with the limitations imposed on them by their illnesses.

<sup>78</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>79</sup> 15 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>80</sup> 17 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

For people living with serious mental illness, there is strong evidence that with the proper supports in place they can not only live in the community but also lead fulfilling and productive lives.

A recent report by the Community Mental Health Evaluation Initiative in Ontario, for example, concluded that programs such as Intensive Case Management or Assertive Community Treatment that are designed to assist people living with serious mental illness to remain in the community were “helping clients decrease their reliance on institutional care and improve their quality of life.”<sup>81</sup>

The same report referred to data from a study done in Ottawa that indicate that:

...on average, it costs about \$68 per day to provide community-based services to a person with mental illness. To treat the same person in hospital, however, would cost \$481 per day.<sup>82</sup>

Of course, hospital services will always be an essential component in the continuum of care. Nonetheless, another study, from the Eastern Townships region of Quebec, showed that, by providing appropriate community-based facilities, it was possible for a region of close to 300,000 people to meet the long-term needs of people living with serious mental illness in a region that has never had a specialized psychiatric institution.<sup>83</sup>

An orientation towards the community will mean something different for people experiencing mild to moderate mental health problems. For most of them, contact with the mental health system will occur through a primary health care provider (group or solo), who may or may not connect them subsequently with a specialized mental health service of some kind.

Epidemiological data indicate that, each year, roughly 3% of the population will experience a serious mental illness, and that another 17% or so will experience mild to moderate illness. The full range of services must be available therefore to address the needs of both broad categories of people. Figure 1 provides a graphic representation of a system that places individuals at its centre, and of the types of treatments, supports and services that must be in place to meet the needs of all people who experience mental health problems.

The most appropriate balance among all the various elements will vary from community to community and will likely evolve as more becomes known about what types of intervention genuinely facilitate recovery among those living with the complete range of mental illnesses. However, the starting point for thinking about how to improve the mental health system should be the main types of mental health treatments, supports and services that are currently being deployed. This is what is captured in Figure 1.

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<sup>81</sup> Ontario's Community Mental Health Evaluation Initiative. (October 2004) *Making a Difference*, p. 5.

<sup>82</sup> *Ibid.*, p. 9.

<sup>83</sup> Trudel, J.-F., and Lesage, A. (2005) Le sort des patients souffrant de troubles mentaux très graves et persistants lorsqu'il n'y a pas d'hôpital psychiatrique: étude de cas. *Santé Mentale au Québec*, Vol. XXX, No. 1, pp. 47-71.

### 3.5 INTEGRATION

The separation between services and supports that are delivered through the health care system and those that fall largely under other spheres of responsibility, as illustrated in Figure 1, points to the fact that many institutional and structural roadblocks stand in the way of realizing a “seamless” delivery of mental health supports and services.

On the one hand, within the health sector, mental health services must be integrated with physical health care services. Ways must be found to improve the diagnosis and treatment of many illnesses at the level of primary care, as well as ways to integrate better specialist care with primary care services.

On the other hand, the variety of mental health treatments and services funded by ministries of health must also be integrated with the broader range of services required by people living with mental illness that are the responsibility of the various governmental departments and agencies that deal with income support, housing, employment, etc. Moreover, it is essential that services and supports for people living with both mental illness and addiction be better integrated.

**Many institutional and structural roadblocks stand in the way of realizing a “seamless” delivery of mental health supports and services.**

**The variety of mental health treatments and services funded by ministries of health must also be integrated with the broader range of services required by people living with mental illness.**

**Integration also requires that services and supports will be available to people throughout their lifespan.**

Finally, integration also requires that services and supports will be available to people throughout their lifespan, and that as people’s needs change as a result of aging or circumstances they will still be able to gain access to appropriate services and supports in a “seamless” fashion.

Many challenges must be met to achieve the integration of services and supports that many witnesses insisted was essential to improving access to required services and building a system that encourages recovery. First amongst these is the recognition that integration can take place in many ways, and that it is important therefore to adapt strategies to achieve integration in ways that are appropriate to each community’s particular situation.

In this regard, a report prepared by researchers at the Centre for Addiction and Mental Health, *Strategies for Mental Health Integration*, points out the numerous dimensions to the problem of integrating mental health services. It cites research underlining the need to distinguish among three domains — governance, administration and service delivery.

Governance refers to the part of the system with accountability for system performance and the authority to set strategic direction and policy and to oversee general management and the use of resources. Administration is the domain that supports operations on a daily basis and includes the infrastructure for finance, information, human resources, etc. Service is that part of the organization that provides services and supports directly to consumers.

The report notes that the intensity of integration can vary from loosely connected alliances to highly integrated organizations, as can the degree of formality involved (ranging from informal or verbal agreements to formal policies, rules and procedures).<sup>84</sup> The evidence summarized in the report suggests that it is difficult to draw definitive conclusions regarding the ideal way to achieve integration or system-building. It does not appear that integration is best pursued as a cost-saving measure, or that all approaches to system integration yield the desired results.

Nonetheless, a number of benefits were identified that can be derived from greater integration of mental health services, noting that several studies have demonstrated the positive effects of initiatives where:<sup>85</sup>

- a system manager controls a pooled funding envelope;
- performance targets are set and monitored;
- organization of services in the network is centralized around a core (but not necessarily consolidated) agency;
- the system manager has control over inpatient services and monitors admissions.

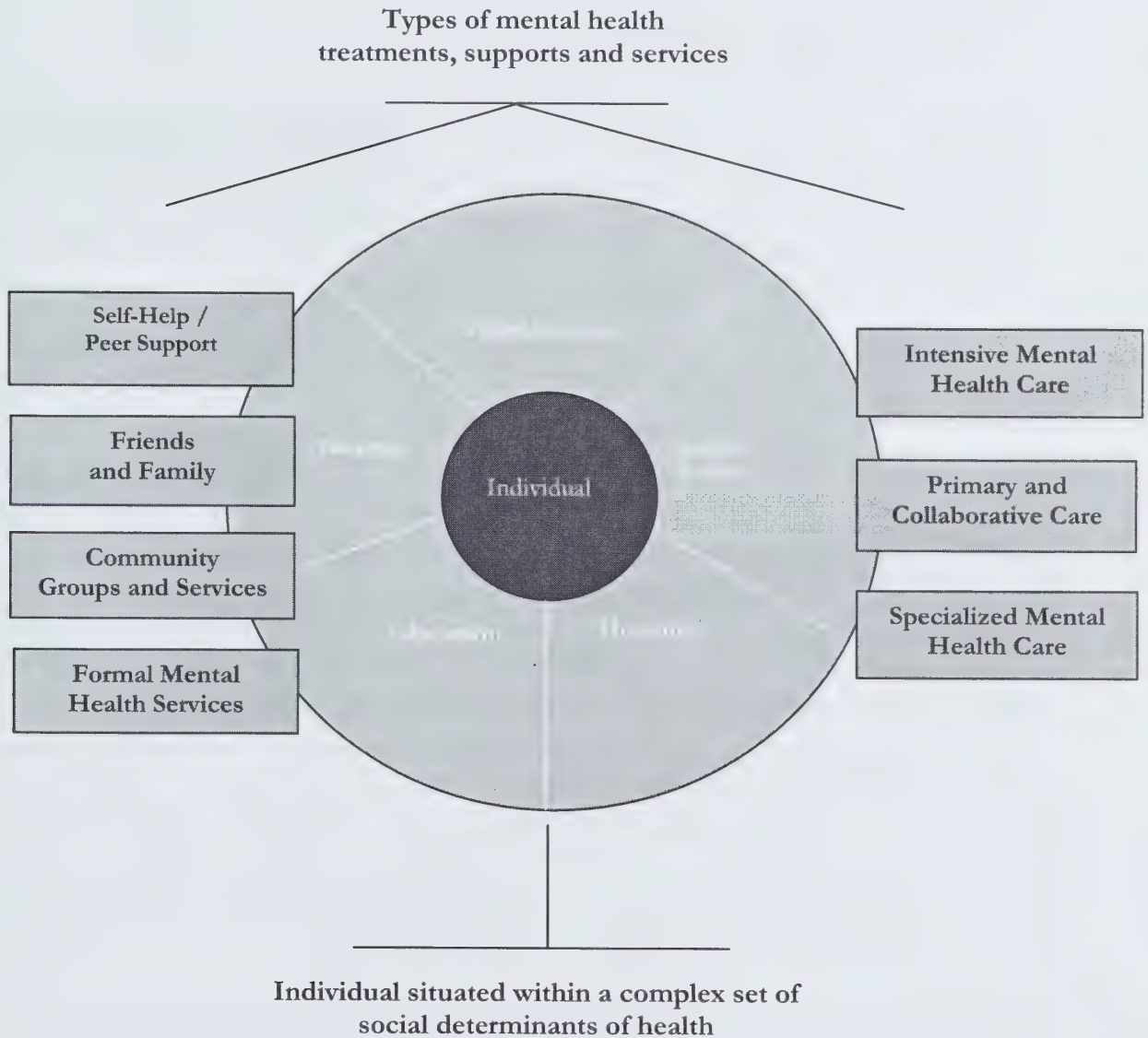
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<sup>84</sup> Centre for Addiction and Mental Health. (2001) *Strategies for Mental Health Integration: A Review*, p. 13.

<sup>85</sup> *Ibid.*

**Figure 1**

Source: Adapted from New Brunswick Department of Health and Wellness, *Community Mental Health Centres: Programs and Services*, p. 3, accessed at: <http://www.gnb.ca/0055/cmhcse.asp>



Others have also commented on the fundamental challenges involved in changing governance structures in the broader health care sector. Mintzberg and Glouberman, for example, have noted that:

Clinical activities cannot be coordinated by managerial interventions — not by outside bosses or coordinators, not by administrative systems, not by discussions of “quality” disconnected from the delivery of it, not by all that constant reorganizing... *Management of clinical operations will have to be effected by the managed, not the managers.*<sup>86</sup>

In March 2000, Ontario’s Health Services Restructuring Commission (HSRC), chaired by Duncan Sinclair, published a report reflecting on its mandate and attempts to restructure the hospital system in Ontario. The HSRC made the following observations about organizational change and governance:

**It is important to allow regions and communities to pursue forms of integration that are appropriate to their particular situations.**

- There is no one best system/ model of governance, but “there is a need to find better ways to promote greater integration, efficiencies and effectiveness across the various components of the health system.”
- New governance models should emerge which “allow individual organizations to use their strengths and talents” while preserving and enhancing organizational distinctiveness.<sup>87</sup>

Finally, in a paper on “Mandated Collaboration,” Steve Lurie looked at the implications for mental health reform of the fact that “there is limited evidence that structural or organizational reform improves clinical outcomes.”<sup>88</sup> The general lessons he drew with regard to efforts at system integration include the following:

- one size doesn’t fit all
- use best practices and unified funding models to drive system change
- there is a need to attend to corporate culture and human resource issues if attempting structural change or alliance building

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<sup>86</sup> Glouberman, S. and Mintzberg, H. (Winter 2001) Managing the Care of Health and the Cure of Disease, Parts I and II. In Health Care Management Review, Vol. 26, Issue 1, pp. 72-4 (emphasis added). Everett, B., Lurie, S. and Higgins, C. (2001). The Whole Picture: A provincial framework for redesigning the Ontario mental health system. Canadian Mental Health Association, Ontario Division, and Ontario Federation of Community Mental Health and Addiction Programs.

<sup>87</sup> Ontario Health Services Restructuring Commission. (2000) A Legacy Report: Looking Back, Looking Forward. Quoted in Everett, Lurie, and Higgins (2001).

<sup>88</sup> Lurie, S. (June 2002) Mandated Collaboration: Command and Control or Emergent Process. Canadian Mental Health Association, Metro Toronto Branch, p. 37.

- Rome wasn't built in a day; the development of effective collaborative relationships take time
- there is a need to experiment, evaluate and learn from experience

It is possible to identify many potential ways of improving integration of mental health services and supports. A partial list could include:

- expanding the use of multidisciplinary teams, shared care and collaborative care arrangements
- developing common assessment protocols
- pooling funding
- putting in place registries of available services
- linking data systems and electronic health records
- creating mental health authorities or engaging in area planning
- developing common service protocols and care pathways

The Committee believes that it is important to allow regions and communities to pursue forms of integration that are appropriate to their particular situations. Each community and region will have to choose strategies that take into account its readiness for change, and the available opportunities for improving access to services.

**It is critical that integration be recognized as an essential dimension of building a recovery-oriented mental health system.**

For example, we will later describe some of the ways that mental health services have been successfully integrated in Brandon, Manitoba. While Brandon's experience is exemplary in many ways, it is also clear that it would be extremely difficult to replicate that experience precisely in other communities across the country. Not only has it taken 25 years of hard work by a dedicated group of people in Brandon to restructure and coordinate their community mental health services, but their success is also built upon a very particular history of deinstitutionalization that provided a context for change that does not exist in many other communities. Nevertheless, a lot can be learned from that experience.

While the approach to integration must be based on the particular history and circumstances of each community, it is still critical that integration be recognized as an essential dimension of building a recovery-oriented mental health system. Integration in some fashion is an indispensable ingredient to provide people living with mental illness and addiction with a truly seamless delivery system that can meet their needs throughout their lifespan.

While there will never be a single template for how this is to be accomplished, the goal of recovery is one that must drive efforts to reform the mental health system. Integration must be seen as a means to achieving that goal and not as an end in itself — it must serve the

objective of improving the range, affordability, quality, and accessibility of services. This requires measurement, accountability, and a commitment to change.

### 3.6 TURNING THE VISION INTO REALITY

The remainder of this report will describe the changes required if progress is to be made in creating a recovery-oriented mental health system that rests firmly on the three pillars of choice, community and integration. There are many concrete hurdles to be overcome, many of which were documented in the Committee's background reports and eloquently recapitulated in the testimony of the witnesses and participants in the Committee's e-consultations who were quoted in the first two chapters of this report.

At times the task can seem overwhelming, in part because making progress in any one area seems to depend on making progress in them all. The Committee firmly believes that despite the scale of the challenge it is possible to move forward, but only if a strategic plan is developed and a step-by-step approach is adopted toward its implementation. We recognize that it is indeed impossible to transform the entire mental health delivery system in one fell swoop. However, pragmatic reform that enables real improvements to be made in the lives of people living with mental illness and addiction is achievable and it must happen, and soon.

**The Committee firmly believes that despite the scale of the challenge it is possible to move forward, but only if a strategic plan is developed and a step-by-step approach is adopted toward its implementation.**

The Committee is acutely aware that this report will not contain all the answers to the many challenges that confront many thousands of Canadians concerned with mental health and addiction. A parliamentary report in itself can never guarantee that action on its recommendations will follow. Moreover, the effort to implement a reform plan must extend over a considerable period of time.<sup>89</sup>

Nevertheless, the Committee has been encouraged in the course of its public hearings by the sense that the time may just be right to move forward in key areas. Moreover, as will become apparent, the Committee has worked very hard to ensure that the momentum for change that has been building during the three years in which we have been working on this issue can be sustained. In this regard, one of the recommendations in this report (see Chapter 16) stands out as key to the process of transforming the mental health delivery system in Canada.

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<sup>89</sup> In this regard, the Committee takes note of the fact that even in countries such as Australia that have set an international standard in mental health planning, there are indications of how difficult it is to sustain the momentum for reform. In a recent (May 2005) report to a parliamentary committee titled *Not a Failure of Policy, It Is a Failure of Implementation and Delivery*, the Mental Health Commission of Australia writes that "the last five or six years have seen what was a significant policy initiative lose direction and show signs of stress and indeed crisis." It identifies a number of causes for this evolution, including: (a) "the burden of mental illness and associated disability within the community is not matched by the funding allocated to prevent, relieve and rehabilitate people experiencing mental health illness"; (b) "there is a significant mismatch between the community based mental health service model and the current system of still allocating funding largely on the old service model of 'beds and buildings'; and (c) "the failure to agree on and implement a national framework for accountability."

The Committee believes that only if the Canadian Mental Health Commission, recommended in Chapter 16, is created immediately following the release of this report, will it be possible to maintain a national focus on mental health issues and bring together all the stakeholders who will have a role to play in transforming the system. In this sense, the new Canadian Mental Health Commission is an essential mechanism for the realization of the vision outlined in this chapter and for implementing the reform measures described and recommended in the rest of this report.

### 3.7 SUMMARY OF PRINCIPLES

The principles outlined in this chapter can be summarized as follows:

1. While mental illness and physical illness are both like and unlike each other, they must be treated with **equal** seriousness, and people who are living with mental and physical illnesses must be accorded **equal** respect and consideration.
2. The central goal of mental health policy is to create the best possible context for encouraging **recovery**; a focus on recovery places emphasis on wellness as opposed to illness, and sets the goal of facilitating the abilities of people living with mental illness to deal actively with the limits imposed by their conditions and to live meaningful and productive lives.
3. Promoting mental health and recovery from mental illness **requires** interventions that address the **social determinants of health** — in particular those related to income, adequate housing and employment, and participation in social networks.
4. A policy approach based on the idea of recovery must acknowledge that:
  - Each person's path to recovery is unique;
  - Recovery is a process, not an end point;
  - Recovery is an active process in which the individual takes responsibility for his or her own recovery, and success depends upon collaboration among helping friends, family, the community, and professional supports.
5. A focus on recovery will require reorienting the design and delivery of mental health programs; there are three pillars upon which a recovery-oriented system must be founded:
  - **Choice:** Access to a wide range of publicly funded services and supports that offer people living with mental illness the opportunity to choose those that will benefit them most;
  - **Community:** Making these services and supports available in the communities where people live and orienting them toward supporting people living in the community;

- **Integration:** Integration of all types of services and supports across the many levels of government, and across both the public/private and the professional/non-professional divides.
6. Policy decisions about which treatments, services and supports should receive public funding must be based on the best evidence available; this includes findings from the medical sciences, data and analyses from the social sciences, and the testimony of people with direct experience of mental illness.

## APPENDIX: MODELS OF RECOVERY

### 1) Psychosocial Rehabilitation Model

The most widely used rehabilitation model is the Psychosocial Rehabilitation Model (PSR) originated in Boston University.

PSR is a professionally driven model that has shaped the development of many community-based programs and services.<sup>90</sup> It is based on the view that people with a mental illness can recover even though their illness is not cured. PSR focuses on enhancing functional ability and attempts to look at all areas of a person's life, including strengths, resources, and barriers. The PSR approach seeks to improve four main life domains:

- practical skills of personal self-care,
- home management,
- relationships and use of community resources,
- leisure, education, and employment.

The goal is to help people regain social functioning despite their having symptoms, limitations and taking medications. The PSR specialist helps the individual move toward self-selected meaningful life goals and provides appropriate social and therapeutic supports to help them do so. Goal-specific skills are taught to assist individuals to achieve self-sufficiency, building on natural social and community support systems.

Within this model, mental illness is seen as a permanent impairment similar to the way a spinal cord injury produces lasting paralysis. It is considered that people have a “broken brain” and that, with appropriate and adequate supports, they can continue to function in society. However, their impairment remains permanent.<sup>91</sup>

The fundamental principles that underpin PSR can be stated as follows. PSR:

1. Emphasizes the need for individually tailored interventions;
2. Requires either that the individual's capacities be adapted to environmental realities or that the environment be changed to suit the capacities of the individual;
3. Builds on the individual's strengths;
4. Aims to restore hope;
5. Emphasizes the individual's vocational potential;
6. Extends beyond work activities to encompass a full array of social and recreational activities;
7. Actively involves individuals in their own care;
8. Is an ongoing process that must continue over time.

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<sup>90</sup> Jacobson, N., and Curtis, L. (2000) Recovery as Policy in Mental Health Services: Strategies emerging from the States. *Psychiatric Rehabilitation Journal*, Vol. 23, No. 4.

<sup>91</sup> *Ibid.*

Psychosocial rehabilitation focuses on early intervention, wellness, independence, self-determination and most importantly — hope. Cognitive therapy, or the process of learning positive and self-enhancing self-talk, is used to help people make sense of and manage distressing symptoms of illness. Mutual support, through peer support groups, is seen to enhance self-sufficiency and expand social networks, build each person's self-reliance and overcome dependency on professionals.

The belief in the client's personal capacity for growth, the development of helpful partnerships and seamless services built on individual needs and preferences are core to the psychosocial model. Clients receive ongoing evaluation to ensure continuous progress.

Strategies include illness education, family intervention, supported employment, assertive community treatment (ACT), skills training, and cognitive behavioural therapy.

The practice of psychosocial rehabilitation is done by existing professionals such as psychiatrists, psychologists, social workers, occupational therapists and nurses, all with the necessary skills and training, or by persons who have received specific training in psychosocial rehabilitation in university programs.

The “client-centred” approach utilized by PSR specialists has been criticized at times for “colonizing” the life of consumers where professionals are actively involved not only during periods of sickness but when people are healthy as well. There have been instances where professionals have claimed ownership and responsibility not only for illness management but for social, recreational and employment roles as well. This has prompted some consumers to react by saying that “*When you say ‘client-centred’, I feel surrounded.*”<sup>92</sup>

Dr. William Anthony, the “founder” of the psychosocial rehabilitation movement, emphasizes that recovery can occur without professional intervention. The task for professionals is to facilitate this natural process.<sup>93</sup> He named the 1990s the “decade of recovery” because of the gains made in helping people adjust to community living. However, he cautions that 2000 must be the “decade of the person.”

In his view, rehabilitation must be done “with” clients, not “to” them. He believes people can make meaningful choices and recognizes that lip service has been paid to the concept of self-determination. The belief that people with mental illness set unrealistic goals and cannot hold demanding jobs has resulted in professionals taking choices away from consumers “for their own good.” In his words, “If people are allowed to choose they may request something that demands we change our actions or programs.”<sup>94</sup>

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<sup>92</sup> Canadian Collaborative Mental Health Initiative. (2004) Ontario consumer consultations.

<sup>93</sup> Anthony, W. A. (1993) Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, Vol. 16, pp. 11-23.

<sup>94</sup> Anthony, W. A. (2003) The Decade of the Person and the Walls that Divide Us. *Behavioural Healthcare Tomorrow*. <http://www.bu.edu/cpr/catalog/articles/2003/anthony2003c.pdf>.

## 2) Empowerment Model

The consumer advocacy community has championed the empowerment model of Recovery as a means of promoting the idea that psychiatric patients are able to work and live independent lives and should not be defined by their “diagnosis.” Proponents of the empowerment model argue that designating mental illness as a permanent condition is one of the factors that contribute to ostracizing people living with mental illness from society.<sup>95</sup>

For consumer activists, recovery has political as well as personal implications — it is a philosophy with a set of organizing principles and values which can guide the development of supports and services as well as how they are organized and delivered.

On this understanding, to recover is to reclaim one’s life, to be validated as an autonomous, competent individual. It emphasizes that people are responsible for their own lives and affords them the privilege of choice, including the right to make mistakes. Moreover, it insists that professionals cannot manufacture the spirit of recovery.

As one e-consultation respondent told the Committee:

*Systemic change will not come from professionals who experience these illnesses through an academic lens but from the lived experience of consumers and families. Ask a professional what is needed and they will always say more professional service. Ask a consumer and family member and they wish and hope for recovery. To be part of the community, a contributing and valued member of society with friends and [a] safe home. No amount of medication will help achieve those goals. Although for many medication is vitally important for clearing the path to wellness. —Anonymous*

Recovery is understood as a manifestation of personal empowerment. Within this framework, recovery happens when there is a combination of supports to (re)establish social function and sufficient self-management skills to take control of the major decisions affecting one’s life.<sup>96</sup>

According to the Empowerment Connection:

Recovery is the lived experience of persons as they discover, accept, and overcome the challenges of a disability, the effects of a psychiatric diagnosis or emotional or psychological trauma. It is discovering a new sense of self, of hope and purpose within and beyond the limits of these experiences. It is the discovery of one’s own strengths and sense of power and control within oneself and the world. Finally, recovery occurs when a person’s psychiatric diagnosis or emotional trauma is no longer the central focus in that person’s life, but simply becomes a part of who that person is.

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<sup>95</sup> Fisher, D. B. (1999) A New Vision of Recovery: People can fully recover from mental illness; it is not a life-long process. National Empowerment Centre.

[http://www.power2u.org/recovery/new\\_vision.html](http://www.power2u.org/recovery/new_vision.html).

<sup>96</sup> *Ibid.*

It is not just mental illness and psychological trauma that people have to recover from; they also face the task of recovering from the effects of internalized stigma, learned helplessness, institutionalization, poverty, homelessness, and the wounds of spirit breaking.<sup>97</sup>

Empowerment recovery is a values-based approach that puts people first and holds that the experience of illness is not permanent. This means that not only is recovery possible, it is to be expected. Recovery is seen as a continuing internal process that places the person at the centre of his or her own recovery. It is not seen as a linear process with an end point or destination. This approach to recovery also holds that individuals are “expert” in their own care. The re-establishment of social relationships is seen as vital to recovery, particularly with peers who understand viscerally the experience of mental illness.<sup>98</sup>

Empowerment recovery does not suggest that professional services are unimportant or unnecessary. However, such services are not intended to “fix” the person, but rather to support him or her as the individual moves towards a healthy life. Individuals living with mental illness are seen as the agents of change, and professionals are one of the resources to be drawn upon. In this model, psychiatric treatment is viewed as part of self-managed care.

Adopting such an approach implies a shift away from the goal of treatment being the stabilization of illness through symptom reduction. Instead, the goal becomes to assist people to gain greater independence and control over their own lives. Medication is used as a tool to help people reach that goal — not as a solution to their problems. The continued use of medication does not preclude recovery. Rather it is seen as a useful adjunct to help people gain control when they are frightened or confused.

Within this recovery model, supports and services can be accessed without requiring the acceptance of the diagnostic (labelling) process. Professionals help to foster recovery by believing in the capacity of their clients to heal and by acknowledging their right to make decisions, even at the risk of failure. Demanding compliance and conformity with professional authority is considered to interfere with learning how to become self-determining. An essential ingredient of recovery is hope. Recovery requires that everyone be given a chance to get better, at their own pace. The recovery approach asks people what they want and need in order to grow, and provides them with the skills and supports to achieve it.<sup>99</sup>

Changing the relationship between those who have been labelled “mentally ill” and those who have not can also create a common ground. Accepting the possibility that any one of us can experience a mental illness, that, in the words of Dr. John Frank, Scientific Director

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<sup>97</sup> <http://www.empowermentconnection.com/approach.html>.

<sup>98</sup> An Empowerment Model of Recovery from Severe Mental Illness: An Expert Interview with Daniel B. Fisher, MD, PhD. (January 2005) *Medscape, Psychiatry & Mental Health*, Vol. 10, No. 1.

<sup>99</sup> Deegan, P. (1996) Recovery and the Conspiracy of Hope. 6th Annual Mental Health Services Conference of Australia.

of the Institute of Population and Public Health, we “are all at risk at different times in our lives,”<sup>100</sup> helps to remove the stigma engendered through seeing it as “them” and “us.”

Each person’s path to recovery is unique, and what fosters recovery reflects personal experiences and preferences. Recovery may include 12-step programs, developing close, supportive, and mutual friendships, intermittent or ongoing treatment, participation in social or vocational rehabilitation programs, becoming involved in spiritual communities, and/or consumer-/survivor-run support networks and advocacy groups. Power and responsibility must be shared by actively involving consumers and family as key players in mental health planning, organizational governance, system design, evaluation, and service delivery.

Recovery-oriented systems recognize that concepts of recovery need to be taught and create educational opportunities such as workshops and conferences for policy makers, planners, professionals, consumers and family. Consumers are seen as recovery educators. A recovery model would ensure that a percentage of funding is allocated for consumer-run initiatives and support such as peer support, self-help, and economic development initiatives, as well as crisis and respite care programs. It includes recognition that building the capacity for sustained and meaningful participation by consumers and family organizations requires long-term adequate funding, management training, and organizational support to be successful

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<sup>100</sup> Gordon, A. (2005) Combating the stigma of mental disorders: New initiative to kick off mental health week. *Toronto Star*, 29 April 2005.



*Accountability means requiring the mental health system to comply with the law. —Jennifer Chambers<sup>101</sup>*

## 4.1 ACCESS TO PERSONAL HEALTH INFORMATION

### 4.1.1 Background

The issue of the right to privacy of persons living with mental illness and addiction, and the impact of that right on their family caregivers, has been raised repeatedly by witnesses at public hearings since the Committee began its work over two years ago. In its earlier review of this difficult issue, the Committee noted that:

**The Committee is not convinced that the issue of confidentiality represents conflict solely between persons living with mental illness and their family caregivers. The Committee is also sceptical that existing legal protections of the right to privacy of persons living with mental illness are unworkable.**

Concern arising from strict observation of privacy and confidentiality rules also extends to the family of individuals with mental illness and addiction. Without the patient's permission, which those with mental illness/addiction may not be competent to give, a physician cannot share personal information with his or her caregivers, parents, siblings or children.<sup>102</sup>

With respect to privacy and confidentiality issues, the Committee is well aware that any erosion of privacy and confidentiality protections can have serious negative consequences on an individual's trust in his or her caregivers. However, as noted above, witnesses have told us that rigid adherence to privacy and confidentiality rules in certain circumstances can work against the interests of individuals whose mental health is compromised. The unique challenges they describe must be recognized when developing, interpreting and applying privacy and confidentiality rules, so as to allow health care providers and family caregivers to provide patients with the much needed support they sometimes require.<sup>103</sup>

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<sup>101</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>102</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 11, Section 11.3, p. 238.

<sup>103</sup> *Ibid.*, Chapter 11, Section 11.7, p. 246.

Such was the Committee's concern that in the aftermath of its first round of public hearings, in its third interim report it posed a series of questions to elicit additional comment from the public. Specifically, it asked:

Are there mental health systems that have better, clearer procedures and consent forms for releasing information to families? What changes are required in Canada to facilitate the sharing of information about a patient's/client's condition with his or her family? Should there be greater consistency and standardization of information sharing practices in Canada with respect to patients with mental illness and addiction?<sup>104</sup>

In the subsequent public consultations there was extensive comment and debate on this topic and feedback was received from those living with mental illness, and their families. Not surprisingly, no clear consensus emerged.

To illustrate, Ron Carten, Coordinator of the Vancouver-Richmond Mental Health Network, and a person with direct experience of mental illness, stated that:

*Regarding children, I do not think confidentiality should be extended to exclude parents. Parents need to know about their children and have a right to know about their children.*

*Regarding adults, I think we have to treat the mental patient, regardless of his relationship to his family, as an adult and an individual with rights and dignity, and therefore, notwithstanding the family's interests in their family member, confidentiality should stand.*<sup>105</sup>

Joan Nazif, of the Family Advisory Committee of Vancouver Mental Health Services, presented the opposite view:

*A major concern for families is to access information about their seriously mentally ill family member. Family members are not interested in the confidential discussions between therapists and patient but they do need to know the diagnosis, care plan, medication, safety issues, so that they can continue to provide the best support.*

[...]

*Now, there are instances, I am sure, where families are not therapeutic for the individual. We are family members who love our family member, and we give*

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<sup>104</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 3 — Mental Health, Mental Illness and Addiction: Issues and Options for Canada, Chapter 6, Section 6.5, p. 45.

<sup>105</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42471-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42471-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*support to our loved one 24 hours a day. I mean, I will be there for my daughter as long as I live.*<sup>106</sup>

Having regard to all the evidence and opinion, the Committee is not convinced that the issue of confidentiality represents conflict solely between persons living with mental illness and their family caregivers. The Committee is also sceptical that existing legal protections of the right to privacy of persons living with mental illness are unworkable. That is not to say that reform of the laws governing privacy is unnecessary, but that it should not be considered in isolation from the more general debate about transforming the whole mental health system.

#### **4.1.2 Finding a Way Forward**

The *Charter* rights of persons living with mental illness and addiction, and in particular their right to equality, must be respected. These affected Canadians are full members of our society. Questions concerning their mental capacity cannot be used as a pretext for watering down or stripping away any of their civil liberties or human rights.

This having been said, the Committee is not insensitive to the circumstances of family caregivers. Many who appeared before the Committee expressed their keen desire to assist and support their loved one in the recovery process. Indeed, it was their forceful and articulate arguments that consistently held this issue at the forefront of our deliberations.

##### **4.1.2.1 Privacy and the Age of Consent**

Dealing first with the right to privacy for children and youth, parents want and need full information about the health of their children. The claim of access to personal health information by family caregivers is clearly strengthened when a child is involved. Nevertheless, the Committee appreciates that, prior to achieving the age of majority, some people may be fully capable of deciding who should have access to their personal health information and to what extent.

Given the lack of consistency across Canadian jurisdictions with respect to applicable privacy legislation, and varying capacities on the part of children and youth to consent to their own health treatment, the Committee recommends:

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**That the provinces and territories establish a uniform age at which youth are deemed capable of consenting to the collection, use and disclosure of their personal health information.**

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<sup>106</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

#### 4.1.2.2 The Role of Health Care Professionals

Some witnesses suggested that health care professionals were not doing enough to ensure that existing legislation governing access to personal health information was applied consistently and to its fullest extent. For example, Brenda McPherson, Provincial Coordinator, Psychiatric Patient Advocate Services, New Brunswick, testified that:

**I think we have to open up that door for doctors to say, "Let me look at this. Let me talk with your son, or your daughter, or your mother. Let me try to help this process."**

**—Brenda McPherson**

*In terms of parents having information, health professionals need to be more informed about how they need to play an active role in getting consent from patients. It is a matter of signing your name on a piece of paper and saying, "Yes, it is okay for my doctor to talk with my parents."*

*I think we tend to overdramatize the issue of consent, and we should stop doing that. Health care professionals need to understand the importance of that. Maybe we need to open up that door, and ask, how can we best educate our health professionals to make them understand, and make them more aware that ethically, this is not damaging to them as professionals, but it is damaging to your client if they do not?*

*[...] It is twofold. I would say, one, educate our health professionals as to the importance of getting consent... I do not think they are doing it, and they are not looking at doing it. I think they are sticking to the, "I cannot do it and that is it." [...] I think we have to open up that door for doctors to say, "Let me look at this. Let me talk with your son, or your daughter, or your mother. Let me try to help this process." Have doctors say this rather than, "No, I cannot because I am bound by ethics."<sup>107</sup>*

Her words were echoed by France Daigle, Suicide Prevention Program, New Brunswick Ministry of Health, who stated that:

**The Committee believes that in circumstances where there is clear, serious and imminent danger, health care professionals may have an overriding duty in law to warn third parties and thereby protect the safety of the patient. It does not agree, however, that the role of health care professionals is to act as quasi-judicial arbiters.**

*...the first thing people say is, "I cannot tell you anything because of confidentiality." However, when you have someone that is at risk for suicide, and as much as I do respect confidentiality, because we have a code of ethics, what is more important? You have to let the family and other people know.*

<sup>107</sup> 11 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*I found that sometimes as caregiver, family members, or professionals, we hide behind this confidentiality. We have to start working together.*<sup>108</sup>

The Committee believes that health professionals have an important role to play in improving the flow of information between persons living with mental illness, and their families. Therefore, it recommends:

2	<p><b>That health care professionals take an active role in promoting communication between persons living with mental illness and their families. This includes asking persons living with mental illness if they wish to share personal health information with their families, providing them with copies of the necessary consent forms, and assisting them in filling them out.</b></p>
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Joan Nazif suggested that the role of health care professionals be expanded still further. She noted that:

*Like many other provinces, we have the Freedom of Information and Protection of Privacy Act, FOIPPA, but unlike some other provinces, we are fortunate to have guidelines for FOIPPA. The guidelines, written by our provincial government Ministry of Health, state that a health provider may decide to share information with family or another third party.*<sup>109</sup>

The Committee believes that in circumstances where there is clear, serious and imminent danger, health care professionals may have an overriding duty in law to warn third parties and thereby protect the safety of the patient. It does not agree, however, that the role of health care professionals is to act as quasi-judicial arbiters between persons living with mental illness and their families, or to take the role of privacy commissioners or judges in interpreting legislation governing the right of privacy. Therefore, it recommends:

3	<p><b>That health care professionals have discretion to release personal health information, without consent, in circumstances of clear, serious and imminent danger for the purposes of warning third parties and protecting the safety of the patient.</b></p> <p><b>That this discretion be governed by a clearly defined legal standard set out in legislation, and subject to review by privacy commissioners and the courts.</b></p>
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<sup>108</sup> 11 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>109</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42470-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42470-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

#### 4.1.2.3 Substitute Decision Makers and Advance Directives

The Committee was concerned that many families seemed unaware of the fact that provincial laws often anticipate incapacity on the part of persons living with mental illness and contain specific provisions to facilitate the flow of personal health information to them. For example, under Ontario law a mentally capable person may appoint a substitute decision maker and grant him or her the right to access some or all of his/her personal health information. Persons with direct experience of mental illness, like Ron Carten, raised this as an alternative to weakening privacy protections:

*Well, you are questioning whether or not the person who is diagnosed with the mental illness can make a decision. There are such things as advance directives. The Representation Agreement Act of British Columbia provides for those, but explicitly excludes people with mental illness. If that right were granted to people with mental illness, they could appoint someone ahead of time to make decisions for them when they are not capable of doing so.*<sup>110</sup>

**Making advance directives and appointing substitute decision makers would ensure family access to personal health information while also preserving the autonomy and dignity of persons living with mental illness.**

Making advance directives and appointing substitute decision makers is a relatively simple process. If it were to be widely employed, it would ensure family access to personal health information while also preserving the autonomy and dignity of persons living with mental illness. For this reason the Committee recommends:

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|---|---|
| 4 | <p><b>That all provinces and territories empower mentally capable persons, through legislation, to appoint substitute decision makers and to give advance directives regarding access to their personal health information.</b></p> <p><b>That provisions in any provincial legislation that have the effect of barring persons from giving advance directives regarding mental health treatment decisions be repealed.</b></p> <p><b>That all provinces and territories make available forms and information kits explaining how to appoint substitute decision makers and make advance directives.</b></p> <p><b>That all provinces and territories make available community-based legal services to assist individuals in appointing substitute decision makers and making advance directives.</b></p> |
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<sup>110</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42471-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/42471-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

That all provinces and territories undertake public education campaigns to educate persons with mental illness, and their families, about the right to appoint a substitute decision maker and make an advance directive.

#### 4.1.2.4 Filling the Gap

The Committee is aware that pre-planning will not occur in every case. Individuals may not anticipate becoming ill and therefore may not name a substitute decision maker or make an advance directive. After all, it is not uncommon for people, particularly young people, to die without having given any thought to estate planning, let alone preparing a valid will.

**The best we can hope for is to offer Canadians and their families the opportunity to plan for their being incapacitated in the future and, should they fail to do so, offer them a second window of opportunity.**

In cases such as these, it is important that some legal mechanism be put in place to fill the gap. It is reasonable to assume that individuals affected by a mental illness would want and expect their spouses, children, parents or other family members to care for them in the same way they would in the case of an unanticipated physical illness. It is also reasonable to expect that those family caregivers would require access to some of the relevant personal health information in order to better care for their sick loved one. Therefore, the Committee recommends:

- 5 That where a person is diagnosed with a mental illness that results in his/her being found mentally incapable, and where there is no previous history of mental illness or finding of mental incapacity, and where there is no named substitute decision maker or advance directive, the law create a presumption in favour of disclosure of personal health information to the affected person's family caregiver(s).  
That the provinces and territories enact uniform legislation setting out this presumption.  
That the legislation specify an "order of precedence" for relatives (i.e., if the person is married, or living in a common-law relationship, disclosure would be to his or her spouse or common-law partner, and if there is no spouse or common-law partner, to the person's children, etc.).

That the legislation specify the information to be disclosed, including: diagnosis, prognosis, care plan (including treatment options, treatment prescribed, and management of side-effects), level of compliance with the treatment regime, and safety issues (e.g., risk of suicide).

That the legislation specifically bar the release of counselling records.

That the legislation oblige the person disclosing the personal health information to notify the mentally incapable person, in writing, of the information disclosed, and to whom it was disclosed.

The Committee realizes that this is not an ideal solution and that families caring for someone affected by a mental illness are unlikely to be fully satisfied. However, it is not our role to compel persons living with mental illness to make any particular decision.

The best we can hope for is to offer Canadians and their families the opportunity to plan for their being incapacitated in the future and, should they fail to do so, offer them a second window of opportunity. If, however, having regained his or her mental capacity someone elects to preclude his or her loved ones from sharing relevant personal health information from that point on, the Committee respects that the choice is that individual's to make.

## 4.2 CHARTER OF PATIENTS' RIGHTS

### 4.2.1 Background

The Committee has struggled long and hard with the issue of how to ensure that health care patients receive the care and support they need. In its earlier report entitled *The Health of Canadians — The Federal Role*, the Committee put forward the idea of adopting a charter of patients' rights "as the means of enforcing maximum waiting time standards."<sup>111</sup> Although this option was eventually rejected in favour of other less legalistic approaches, the idea did not perish.

**The Committee acknowledges the support shown for a patients' charter in its second on-line consultation.**

During the public hearings that preceded publication of the Committee's background reports on mental health, mental illness and addiction, a number of witnesses raised in this new context the option of a patients' charter. The Committee also took note of the robust vision articulated by the Champlain District Mental Health Implementation Task Force in Ontario. It argued for a charter that:

<sup>111</sup> Standing Senate Committee on Social Affairs, Science and Technology. (April 2002) *The Health of Canadians — The Federal Role*, Volume 5, Chapter 2, Section 2.5, p. 60.

...would not be limited to mental health services but would also encompass broader social supports. More precisely, the proposed charter included, for example:

- Mental health services that are safe, secure, evidence-based, timely, culturally appropriate and relevant to the individual's needs;
- Services and supports that encourage the involvement of individuals with mental illness and addiction and are based on the principles of recovery, self-help and independent living and functioning;
- Treatment that is respectful of relevant legislation (Mental Health Act, Canadian Charter of Rights and Freedoms, etc.);
- Respect for privacy and informed choices.<sup>112</sup>

#### 4.2.2 Stakeholder Consultations

Given the level of interest in a patients' mental health charter, the Committee opted to canvass the issue more broadly. In the Committee's second on-line consultation, Canadians were asked whether they favoured a legislated "Charter of Consumers' Rights," and for their views on what it should include.

**The Committee is uncomfortable with the idea of a separate legal regime for persons living with mental illness.**

There was support for adopting a legislated patients' charter, although it was somewhat less popular with family members and service providers than with those living with mental illness.<sup>113</sup> Also, there was support for the inclusion of particular items, such as the right to:

1. mental health/addiction services that are at least of the same quality as other health-related services provided to all Canadians,
2. timely access to mental health/addiction services,
3. mental health/addiction services in [a person's] language of choice and reflecting [their] cultural background,
4. a suitable range of medical and non-medical mental health/addiction services, and,
5. protection from the public expression of views that stigmatize or belittle persons living with mental disorders and/or addiction.<sup>114</sup>

<sup>112</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 8, Section 8.2.7, pp. 164-165.

<sup>113</sup> Ascentum Incorporated. (June 2005) Report on the Online Consultation by the Standing Senate Committee on Social Affairs, Science and Technology, p. 40.

<sup>114</sup> *Ibid.*, p. 38.

Although the results of the second on-line consultation were favourable, the proposed patients' charter was not without its critics. For example, two anonymous participants in wrote:

*Just what we need ... another Charter ... a piece of paper will really help! NOT! Rather than making the lawyers richer and niche activist groups who pursue lawsuits for their own enjoyment more popular, perhaps the government should consider funding these services properly. Now that would be a novel idea! —Anonymous*

*The Federal Government would do well to ensure the current Charter of Rights and Freedoms is enforced rather than developing a second Charter for specific populations. —Anonymous*

### 4.2.3 Roadblocks

While the Committee acknowledges the support shown for a patients' charter in its second on-line consultation, it is mindful of roadblocks to the implementation of such a document. They fall into two general categories.

#### 4.2.3.1 Philosophical Roadblocks

The Committee is uncomfortable with the idea of a separate legal regime for persons living with mental illness. In our view, entrenching rights for a particular segment of the population in a distinct legal instrument places the named group at risk of further alienation and stigmatization. This is particularly true if the proposed patients' charter links obligations or "responsibilities" with the rights it seeks to protect.

**The Committee is concerned that a patients' charter may have the unintended consequence of diluting, rather than augmenting, existing enforcement mechanisms.**

The *Charter of Adult and Family Rights and Responsibilities*<sup>115</sup> serves to illustrate the point. This Charter devotes an entire section to the "responsibility" of maintaining good personal hygiene. It reads as follows:

#### 8. Hygiene

- Pay particular attention to your own hygiene. Poor hygiene is offensive to others
- Bathe, brush you [sic] teeth, and wash your hair regularly
- If this is difficult for you ask for assistance. Perhaps you could make this one of your goals.<sup>116</sup>

<sup>115</sup> The *Charter of Adult and Family Rights and Responsibilities* was prepared by The Adult and Family Rights and Responsibilities Charter Committee of Cranbrook, British Columbia.

<sup>116</sup> The Adult and Family Rights and Responsibilities Charter Committee. (May 2003) *Charter of Adult and Family Rights and Responsibilities*, p. 12.

While the Committee does not wish to be overly critical of the efforts of a dedicated group of concerned citizens, it questions the utility of a patients' charter that would link the violation of constitutional rights, such as freedom from arbitrary detention, with the failure to act "responsibly" (e.g., defined as failure to wash one's hair).

The Committee is similarly concerned that a patients' charter may have the unintended consequence of diluting, rather than augmenting, existing enforcement mechanisms. Including a legal right within a patients' charter may result in complaints being diverted to other bodies for decision, away from quasi-judicial or judicial enforcement mechanisms in which uniform legal standards apply.

The *Bill of Client Rights*,<sup>117</sup> of the Centre for Addiction and Mental Health (CAMH) in Toronto, is used here for illustrative purposes. This document, which is to be distinguished from *The Charter of Adult and Family Rights and Responsibilities*, is a comprehensive rights-based instrument which in our view has the potential to fulfill its intended mandate to promote "...the dignity and worth of all of the people who use the services of the Centre for Addiction and Mental Health."<sup>118</sup> The difficulty, however, is that it strays into the realm of pre-existing legal rights.

**Our preferred course of action would be to facilitate access to personal health information in accordance with the procedures and standards set out in existing privacy laws. The suggestion that persons living with mental illness rely on alternative complaint mechanisms makes us uneasy.**

Section 6(4) of the *Bill of Client Rights* provides that "every client has the right to view her/his clinical records without undue difficulty."<sup>119</sup> It is not clear why this provision is included because in Ontario the *Personal Health Information Protection Act* establishes:

...a formal process for individuals to access and correct their own personal health information, within specified time frames and the right to complain if an access or correction request is denied.<sup>120</sup>

Complaints are adjudicated by the Information and Privacy Commission of Ontario, which has broad powers to enforce the Act. Also, the Act provides for fines of up to \$250,000 for organizations that commit offences set out in it. The unnecessary duplication puzzles the Committee.

The Committee believes strongly that all Canadians should be afforded equal protection and equal benefit under the law. This includes having their rights spelled out and enforced in a uniform way. Therefore, our preferred course of action would be to facilitate access to personal health information in accordance with the procedures and standards set out in

<sup>117</sup> The *Bill of Client Rights* was developed by the clients, families and staff of the Centre for Addiction and Mental Health in Toronto, Ontario, and endorsed by its Board of Trustees.

<sup>118</sup> Centre for Addiction and Mental Health. *Bill of Client Rights*.

<sup>119</sup> *Ibid.*, Right #6(4), p. 5.

<sup>120</sup> Information and Privacy Commission of Ontario. Frequently Asked Questions: Personal Health Information Protection Act - What rights do individuals have?  
[http://www.ipc.on.ca/scripts/index.asp?action=31&P\\_ID=15371&N\\_ID=1&U\\_ID=0&LG\\_ID=1#individuals](http://www.ipc.on.ca/scripts/index.asp?action=31&P_ID=15371&N_ID=1&U_ID=0&LG_ID=1#individuals).

existing privacy laws. This is why the suggestion that persons living with mental illness rely on alternative complaint mechanisms makes us uneasy.

The Committee appreciates that the *Bill of Client Rights* does not preclude CAMH clients from availing themselves of the enforcement mechanisms set out in the *Personal Health Information Protection Act*. However, we are concerned that those who opt to go this latter route will be viewed as “difficult” or “litigious.” Also, we question whether internal complaint mechanisms, particularly in the absence of third-party adjudication and clearly defined sanctions, will yield equivalent results for complainants.

#### **4.2.3.2 Practical Roadblocks**

A number of options for implementing a Charter of Patients’ Rights for mental health services have been suggested. These include creating a Canada Mental Health Act; amending the *Canadian Human Rights Act*; and creating a separate piece of rights legislation to be enacted by Parliament and the provincial and territorial legislatures.

#### **4.2.3.3 Canada Mental Health Act**

One possibility would be to establish a federal Mental Health Act setting out the rights of persons living with mental illness with respect to mental health services. However, there are a number of significant difficulties associated with such a proposal.

The primary barrier relates to the division of powers in the Canadian constitution. With some exceptions, provinces generally have jurisdiction over health, including over hospitals, the direct delivery of most medical services, the education of physicians, and other related functions.<sup>121</sup> Mental health services are primarily under provincial jurisdiction.

Under the Canada Health Transfer (CHT), the federal spending power is used to influence the Canadian medicare system.<sup>122</sup> The same power is also used to set national standards through the *Canada Health Act*, the purpose of which is “to establish criteria and conditions in respect of insured health services and extended health care services provided under provincial law that must be met before a full cash contribution can be made.”<sup>123</sup> The *Canada Health Act* allows the amount of money to be transferred under the CHT to be reduced in two ways: one, if a province allows extra-billing<sup>124</sup> or user charges<sup>125</sup> and two, if the health insurance plan does not satisfy the criteria of public administration, comprehensiveness, universality, and portability.

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<sup>121</sup> Young, M. (December 2000) *The Federal Role in Health and Health Care*. TIPS-59E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, p. 1.

<sup>122</sup> *Ibid.*, p. 2.

<sup>123</sup> *Canada Health Act*, c. 6, s. 4.

<sup>124</sup> “Extra-billing” is defined in the *Canada Health Act* as “the billing for an insured health service rendered to an insured person by a medical practitioner or a dentist in an amount in addition to any amount paid or to be paid for that service by the health care insurance plan of a province.”

<sup>125</sup> “User charge” is defined in the *Canada Health Act* as “any charge for an insured health service that is authorized or permitted by a provincial health care insurance plan that is not payable, directly or indirectly, by a provincial health care insurance plan, but does not include any charge imposed by extra-billing.”

At the same time, it is important to note that the *Canada Health Act* does not cover services provided in a hospital or institution primarily for people with mental illness. This was pointed out by Dr. Sunil Patel, then president of the Canadian Medical Association, when he appeared before the Committee. He suggested that the *Canada Health Act* be amended to include such psychiatric services.<sup>126</sup>

The Committee believes, however, that such an amendment would be largely symbolic for two reasons: first, most stand-alone psychiatric institutions have been closed in favour of providing mental health services in the same hospitals in which physical health services are provided; and second, many services essential to persons living with mental illness (i.e., psychological services or drug therapies) have no or limited coverage under existing provincial health plans. Hence, the Committee does not favour such an amendment to the *Canada Health Act*.

It might nonetheless be possible to develop a Canada Mental Health Act along the lines of the *Canada Health Act*, that is, to tie federal transfers to provincial/territorial compliance with certain principles that guide the provision of mental health services. However, it is difficult to envision how such a law would be enforced, notably because transfers to the provinces are not divided into separate “physical health” and “mental health” categories.

As well, a number of criticisms have been raised with respect to the *Canada Health Act* that illustrate some of the problems that would likely apply to a Canada Mental Health Act. In 2002, the Auditor General pointed out that Health Canada still did not have adequate information to assess the extent of provincial and territorial compliance with the *Canada Health Act* criteria and conditions.<sup>127</sup> The Auditor General was also troubled by the length of time it was taking to resolve compliance issues:

Health Canada has tended to take a non-intrusive approach to administering the Act. However, this approach has not brought about the speedy resolution of issues related to non-compliance with and interpretation of the Act. The majority of the non-compliance issues identified by Health Canada over the past 10 years have remained unresolved for five years or longer.<sup>128</sup>

Furthermore, it is important to recognize that the penalties that have actually been enforced under the *Canada Health Act* relate to user fees and extra-billing; the deduction for non-compliance with the criteria or conditions of the Act has never been used. Given that matters relating to mental health care services

**The potential barriers and concerns outlined suggest that a *Canada Health Act* model would make it a less-than-ideal vehicle for a Charter of Patients' Rights.**

<sup>126</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 3, Section 3.4.1, p. 58.

<sup>127</sup> Report of the Auditor General of Canada — September 2002, Chapter 3, “Health Canada — Federal Support of Health Care Delivery,” paragraph 3.2.

<sup>128</sup> *Ibid.*, paragraph 3.76.

would likely fall under the same broad criteria of “comprehensiveness” and “universality” that apply under the *Canada Health Act*, past practice suggests that if a model similar to the *Canada Health Act* were created, effective enforcement would probably not take place.

The potential barriers and concerns outlined above suggest that a *Canada Health Act* model would make it a less-than-ideal vehicle for a Charter of Patients’ Rights.

#### ***4.2.3.4 Amending the Canadian Human Rights Act***

Another option to implement a Charter of Patients’ Rights would be to amend the *Canadian Human Rights Act*. As described in section 2 of the *Canadian Human Rights Act*, its purpose is to:

extend the laws in Canada to give effect, within the purview of matters coming within the legislative authority of Parliament, to the principle that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated, consistent with their duties and obligations as members of society, without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted.<sup>129</sup>

**The *Canadian Human Rights Act* applies only to areas of federal jurisdiction. Therefore it would not be a useful instrument through which to require amendment of provincial mental health legislation or improve services to persons living with mental illness.**

Some of the activities prohibited by the Act include:

- denying access to goods, services, facilities, or accommodations on a prohibited ground of discrimination (s. 5);
- refusing to employ or refusing to continue to employ an individual on a prohibited ground of discrimination (s. 7);
- publishing or displaying a notice or sign that expresses or implies discrimination or incites others to discriminate (s. 12); and
- telecommunicating hate messages (s. 13).

The *Canadian Human Rights Act* applies only to areas of federal jurisdiction. Therefore it would not be a useful instrument through which to require amendment of provincial mental health legislation or improve services to persons living with mental illness. The Act applies, however, to the provision of health services to First Nations and Inuit, veterans and federal offenders — populations that have certain health services provided to them by the federal government.

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<sup>129</sup> R.S. 1985, c. H-6, s. 2.

Other than requiring that federally regulated service providers avoid discrimination in the provision of services, there is nothing in the *Human Rights Act* that outlines how specific services are to be provided. It may be possible to amend the Act to include specific references to the provision of services. However, such an amendment would have limited application, given that it would apply only to specific populations and in specified circumstances.

#### ***4.2.3.5 Creating a Separate Piece of Legislation to be Enacted by Parliament and the Provincial and Territorial Legislatures***

Given the provincial jurisdiction over health (with the exception of legislation that sets out rights to mental health and other services for populations over which the federal government has responsibility), any legislation enacted by Parliament would likely be limited to making financial transfers to the provinces contingent on their meeting certain criteria, in a similar fashion to the way that the *Canada Health Act* operates.

**Developing model uniform legislation that could be adopted by the provinces and territories would appear to be the option with the greatest chance of leading to the creation of a charter of rights for people living with mental illness. However, given the Committee's objections to a separate legal regime for mental health, this is not a course of action it is prepared to recommend.**

The federal government could, however, invite the provinces and territories to participate in a process to review existing mental health legislation. The goal of the review process would be to develop framework legislation that sets out specific rights to mental health services that could be adopted by the provinces and territories and by the federal government with respect to the populations under its jurisdiction. Such a federal/provincial/territorial review of legislation could take place as part of the Annual Conference of the Federal/Provincial/Territorial Ministers of Health.

Alternatively, it may also be possible to recommend that the Uniform Law Conference of Canada develop model legislation that would set out uniform consumers' rights to mental health services. In 1987, this Conference endorsed a Uniform Mental Health Act developed to ensure that provincial legislation did not violate the *Charter of Rights and Freedoms*.

The Uniform Law Conference has a criminal law group and a civil law group, and was founded to harmonize the laws of provinces. Government policy lawyers and analysts, private lawyers and law reformers gather on a regular basis to consider areas of provincial and territorial law that would benefit from harmonization.<sup>130</sup> Once an area has been studied and draft legislation has been developed, the civil law group adopts the draft legislation and recommends that it be enacted by all relevant governments in Canada.<sup>131</sup>

As mentioned above, it is virtually certain that any attempt by Parliament to establish legislation setting out the rights of persons living with mental illness to mental health services would be rejected by the provinces and territories. The option of making transfer payments contingent on meeting criteria for mental health services is problematic, as

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<sup>130</sup> Uniform Law Conference Web site, <http://www.chlc.ca/en/civil>.

<sup>131</sup> *Ibid.*

described earlier for the *Canada Health Act*. Developing model uniform legislation that could be adopted by the provinces and territories would appear to be the option with the greatest chance of leading to the creation of a charter of rights for people living with mental illness. However, given the Committee's objections to a separate legal regime for mental health, this is not a course of action it is prepared to recommend.

## 4.3 THE MENTAL DISORDER PROVISIONS OF THE *CRIMINAL CODE*

### 4.3.1 Background

Part XX.1 of the *Criminal Code* sets out a comprehensive and independent regime governing accused persons who are found either unfit to stand trial or not criminally responsible for an offence on account of mental disorder. Although it was not our intention, the Committee has found itself drawn into the recent debate surrounding this regime. Given its very recent review and amendment by Parliament, our comments will be limited to those issues that were not resolved by the passage of Bill C-10.<sup>132</sup>

### 4.3.2 Power of Review Boards to Order Assessments

Review Boards have two primary functions. First, when an accused person has been found by a court to be unfit to stand trial:

...the disposition may initially only be a conditional discharge or hospital detention, not an absolute discharge. At each hearing to review the disposition, the Review Board is to determine whether the accused has become fit to stand trial and if so, send him or her back to court. If the court concludes that the accused is indeed fit, a trial may proceed. If the accused is found to remain unfit, he or she will remain subject to further Review Board hearings.<sup>133</sup>

Review Boards may also recommend that a court hold an inquiry where a person poses no significant threat to the public and is unlikely ever to become fit to stand trial. Such an inquiry may result in a stay of proceedings.

**Information needed by Board members to make appropriate dispositions is not always available.**

Second, if a court finds an accused person not criminally responsible on account of mental disorder:

...it may choose one of three dispositions: an absolute discharge, a conditional discharge...or detention in hospital.... Alternatively, and very frequently, the court refers the decision to the Review Board of the appropriate province or territory. Any disposition other than an absolute discharge must be reviewed annually by the Review Board

<sup>132</sup> An Act to amend the Criminal Code (mental disorder) and to make Consequential Amendments to Other Acts, S.C. 2005, c. 22.

<sup>133</sup> Raaflaub, W. (June 2005) The Mental Disorder Provisions of the Criminal Code. PRB 05-05E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, p. 5.

until it determines that the accused is not a significant threat to the safety of the public and discharges him or her absolutely.<sup>134</sup>

In all cases, the law requires that Review Boards impose the least restrictive disposition necessary. However, the Committee was alerted to the fact that information needed by Board members to make appropriate dispositions is not always available. Judge Schneider, Alternate Chair of the Ontario Review Board and the Nunavut Review Board, testified that:

*...the courts rarely, upon a verdict of either unfit to stand trial or not criminally responsible, make an initial disposition and leave it to the review boards. To leave the review board in a position where it does not have, in the spirit of Winko, the full ability to order assessments is really inconsistent with the reasoning of the Supreme Court.*

**(...) the fact that somebody had been seen and an opinion offered with respect to fitness over the last 12 months is really next to irrelevant because fitness is something that fluctuates as a function of the individual's clinical condition; it can change day-to-day, hour-to-hour. So, to limit the board's ability to order assessments in the way that it has been done in C-10 I think is unnecessarily restrictive.**

**—Judge Schneider**

*Just to put this into perspective, it was obviously written by someone who did not understand how the system worked. There is often a report available that has been produced within the last 12 months. The question is whether it is directed to the issues that we have to decide as a review board.*

*[...]The reports that would have been prepared and attached to the information or indictment would have gone to the issue of fitness to stand trial or criminal responsibility. They would not have gone to the issue of least onerous, least restrictive disposition, which is what the board has to decide.<sup>135</sup>*

Following the adoption of Bill C-10, Review Boards may now order assessments where no assessment report is available or no assessment has been conducted in the last 12 months.<sup>136</sup> However, as Judge Schneider noted:

**The Committee is persuaded by the arguments for the need to increase the powers of Review Boards.**

*Particularly with respect to the unfits, the fact that somebody had been seen and an opinion offered with respect to fitness over the last 12 months is really next to irrelevant because fitness is something that fluctuates as a function of the individual's clinical condition; it can change day-to-day, hour-to-hour. So, to limit the board's ability to order assessments in the way that it has been done in C-10 I think is unnecessarily restrictive.*

<sup>134</sup> *Ibid.*

<sup>135</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>136</sup> An Act to amend the Criminal Code (mental disorder) and to make Consequential Amendments to Other Acts, S.C. 2005, c. 22, s. 3.

*I would have simply altered the wording in 672.11 and put in beside “court,” “or review board”. It would have been the simplest way around it.<sup>137</sup>*

Courts have authority to order assessments at any stage of the proceedings against the accused. The Committee is persuaded by the arguments for the need to increase the powers of Review Boards, and therefore recommends:

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That the *Criminal Code* be amended to grant Review Boards the same powers to order mental health assessments as those it currently confers on courts.

#### 4.3.3 Power of Review Boards to Order Treatment

Review Boards have no authority to order a mentally disordered accused to undergo treatment. Courts, on the other hand, are empowered to do so by the *Criminal Code* in very limited circumstances. In his testimony before the Committee, Judge Schneider argued that:

**Review Boards have no authority to order a mentally disordered accused to undergo treatment. Courts, on the other hand, are empowered to do so by the *Criminal Code* in very limited circumstances.**

*The biggest one that was missed in C-10 though, quite apart from the ability to make assessment orders, was the ability of the board to treat accused who come through the system as unfit. Now, we do this quite aggressively in the Mental Health Court because we have got practitioners who are very familiar with the legislation and comfortable in applying it, but if you go outside of this little area here, you will find that treatment orders are generally not made by the court, which means that the accused goes to the provincial or territorial review board as unfit and stays within the jurisdiction of the provincial or territorial review board until they are fit.*

*When the board does not have the ability to order treatment, the same way that the court would have under 672.58, that means that the province or territory where the accused is housed has to rely on whatever the local civil legislation is in order to get them treated. This means that you are going to have somebody unfit staying in the system three, four, five times as long as they would have had the board had just been able to order that they be treated for a period of up to 60 days the same way the courts can under .58.*

<sup>137</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*If the board — which you will remember is made up of a panel of experts — had the same powers as the courts under .58, you would see the unfit people staying in the system for much shorter periods of time. We strongly advocated for that and it just did not receive a mention.*<sup>138</sup>

The issue of involuntary treatment is highly contentious. The Committee heard from many people living with mental illness who strongly oppose forced psychiatric intervention. Their message was unequivocal — imposed treatment is highly damaging to the autonomy and dignity of affected persons:

**The Committee heard from many people living with mental illness who strongly oppose forced psychiatric intervention.**

*In addition to criminal abuse, there is a more consistent abuse of rights of people in the mental health system. It is a constant violation of our right to certain protections under the law.*

*One example is informed consent. Study after study show that few users are informed about the undesirable effects of the psychoactive medications that are prescribed for them. Least restrictive treatment is frequently violated. The right to refuse treatment has really become often an exercise in evaluating the competency of someone in the mental health system when they dare to refuse the offered treatment. —Jennifer Chambers*<sup>139</sup>

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*If psychiatric treatments were effective and relieved suffering, we would not have the crisis that we have in our health care system. People would love their meds. Forced psychiatry exists because many people often do not feel better, or even loathe the drugs and their damaging side effects.*

*[...]Just once, treat a patient against her will and if you do not alleviate suffering, you have lost that person's trust and intensified her fears forever. This is a vital issue for virtually all patients and ex-patients I have ever interviewed. Many are terrified of the mental health system. —Rob Wipond*<sup>140</sup>

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*The option of electroconvulsive therapy in exchange for an early release forced me to sign the consent form; this is not consent, it is coercion. Many things are “voluntary,” but many things that we consent to are not voluntary. It is just like if you put a gun to my head and make me sign over my property to you,*

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<sup>138</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>139</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>140</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*that does not equate to consent and that is virtually what the doctors do to the patients.*

[...]

*I have been phoned by a psychiatrist at my home and been told that I would do what he said, which was to add another pill to my drug cocktail, which at that time was up to four different medications in substantial doses. He told me that if I did not comply he would “send the police to drag me to the hospital in handcuffs.” Those were his words. I was perfectly well at that time.*  
—Francesca Allan<sup>141</sup>

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*I would like to share with you at this point the following quote from the director of the World Health Organization who officially declared a global emergency in human rights and mental health, including this very revealing statement: “A human rights violation is not just a matter of denied access to treatment but also and often consists in treatment itself...” This is something for you to reflect upon. My point in all of this is that we are too prone, we are too much in a rush with the most expensive solutions instead of listening to what people really need. It should not be rocket science, but we make it for some reason.* —Eugene LeBlanc<sup>142</sup>

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*...you cannot believe how horrified I was — I read the presentation of the Schizophrenia Society that suggested you actually recommend removing the right of forensic patients to refuse treatment under the Criminal Code.* —Randy Pritchard<sup>143</sup>

In light of these and other submissions, the Committee has reservations about involuntary treatment although it may be required in very rare circumstances. We recognize that forcing individuals to submit to psychiatric intervention in the absence of their, or their substitute decision makers', consent has real and profound consequences for their autonomy and dignity. Moreover, doing so may violate their *Charter* rights.

Having said that, the powers granted to courts by the *Criminal Code* permit involuntary treatment in very limited circumstances. Treatment dispositions may be made on application by the prosecutor for the sole purpose of making a mentally disordered accused fit to stand trial. Medical evidence must be presented, the disposition is limited to 60 days, and neither

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<sup>141</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>142</sup> 11 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eve-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eve-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>143</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

psychosurgery nor electroconvulsive therapy may be administered. Further, the accused is entitled to challenge the treatment disposition.

We acknowledge the objections to forced psychiatric intervention made to us by persons living with mental illness, and we respect them. We also recognize, however, that the need to shorten the period of time that individuals found unfit to stand trial stay in the system is pressing and substantial. The following decision was not taken easily or lightly. However, the singular purpose of the treatment disposition, coupled with the short time limit, the prohibition of certain highly invasive therapies, and the existing procedural safeguards, give the Committee substantial comfort. Therefore, we recommend:

**We recognize, however, that the need to shorten the period of time that individuals found unfit to stand trial stay in the system is pressing and substantial.**

7

**That the *Criminal Code* be amended to grant Review Boards the same powers to order treatment as those it currently confers on courts.**

#### 4.3.4 Fitness to be Sentenced

Currently, there is a gap in the law pertaining to the issue of fitness to stand trial. This gap arises when a person becomes unfit *after* a verdict has been reached. In other words, the person is not “unfit to stand trial,” but is instead “unfit to be sentenced.” Judge Schneider explained it as follows:

**Currently, there is a gap in the law pertaining to the issue of fitness to stand trial. This gap arises when a person becomes unfit after a verdict has been reached.**

*The other major flaw, and I do not think it was addressed in Bill C-10, was altering the definition of “unfit to stand trial” to include the window up to and including the end of sentencing. I think it remains untouched as going to the end of the verdict, which leaves a legal lacuna if the accused happens to post-verdict get unfit prior to being sentenced.*

*There is a decision by the name of Balliram from Ontario Superior Court, a decision of Justice McWatt, who actually reads in an expanded interpretation of section 2 dealing with “unfit to stand trial”. We were hoping that Parliament would pick up on that in C-10 but they did not.<sup>144</sup>*

These concerns were echoed by Judge Carruthers, Chair of the Ontario Review Board, who testified that:

<sup>144</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*From a practical point of view, many times a person has decompensated after verdict, pending, say, a dangerous offender application. You are in irons because the person is not qualified or capable of being sentenced, but he has been convicted, and it is crazy to not extend the definition as [Judge Schneider] says from "verdict" to include "sentence," and then the whole thing is covered.<sup>145</sup>*

While this issue was not addressed by Bill C-10, it was raised and commented on by the Honourable Irwin Cotler, Minister of Justice and Attorney General of Canada, appearing before the Standing Senate Committee on Legal and Constitutional Affairs to address the proposed legislation. He stated that:

**The Committee is concerned that the Criminal Code does not currently provide a way to deal with convicted persons who become unfit to be sentenced after a verdict has been reached.**

*On the issue of fitness to be sentenced, because reference was made to that, Bill C-10 does not include amendments to provide for a verdict of "unfit to be sentenced" or to provide for assessments at the time of sentencing. This is an important issue on which we felt further research and consultation is needed. Therefore, I share this with your committee as well.*

*The specific amendments that may be needed here relate as much to the principles of sentencing as they do to the law of governing those with a mental disorder. The Department of Justice has commissioned academic research on this issue that suggests that unfitness at the time of sentence requires a different conceptualization or test for fitness and different consequences from those that would follow from a finding of unfit to stand trial.*

*While I agree that this issue must be addressed, we have not included specific amendments in Bill C-10 in relation to it. Amendments may be considered for inclusion in a forthcoming criminal law amendment bill following further consideration and consultation with provincial and territorial ministers responsible for justice, to which this has been referred.<sup>146</sup>*

The Committee is concerned that the *Criminal Code* does not currently provide a way to deal with convicted persons who become unfit to be sentenced after a verdict has been reached. However, given the complexity of the issue and the fact that the Government of Canada is currently taking steps to address it, we believe that putting forward a specific proposal at this time would be premature. Instead, we recommend:

<sup>145</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>146</sup> 13 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/lega-e/09eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=11](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/lega-e/09eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=11).

That the Government of Canada, in consultation with provincial and territorial ministers responsible for justice, develop proposed amendments to the *Criminal Code* to address the issue of convicted persons who become unfit to be sentenced after a verdict has been reached.

That these amendments be brought before Parliament within one year of the tabling of this report in the Senate.



Senate



Sénat

CANADA

# DE L'OMBRE À LA LUMIÈRE

*La transformation des services concernant  
la santé mentale, la maladie mentale  
et la toxicomanie au Canada*

Rapport final du  
Comité sénatorial permanent des affaires sociales, des sciences et de la technologie

L'honorable Michael J.L. Kirby, président  
L'honorable Wilbert Joseph Keon, vice-président

Mai 2006

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Le Comité sénatorial permanent des affaires sociales, des sciences  
et de la technologie

Rapport final au sujet de:  
La santé mentale, la maladie mentale et la toxicomanie

## DE L'OMBRE À LA LUMIÈRE

LA TRANSFORMATION DES SERVICES CONCERNANT LA SANTÉ MENTALE,  
LA MALADIE MENTALE ET LA TOXICOMANIE AU CANADA

*Président*

L'honorable Michael J.L. Kirby

*Vice-président*

L'honorable Wilbert Joseph Keon

Mai 2006



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Extrait des *Journaux du Sénat* du jeudi 7 octobre 2004:

L'honorable sénateur Kirby propose, appuyé par l'honorable sénateur Losier-Cool,

Que le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie soit autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système de soins de santé au Canada en octobre 2002 et les développements subséquents. En particulier, le Comité doit être autorisé à examiner la santé mentale et la maladie mentale;

Que les mémoires reçus et les témoignages entendus sur l'étude de la santé mentale et des maladies mentales par le Comité durant la trente-septième législature soient déferés au Comité;

Que le Comité présente son rapport final au plus tard le 16 décembre 2005 et qu'il conserve tous les pouvoirs nécessaires pour diffuser ses conclusions jusqu'au 31 mars 2006.

La motion, mise aux voix, est adoptée.

---

Extrait des *Journaux du Sénat* du jeudi 20 octobre 2005:

L'honorable sénateur Kirby propose, appuyé par l'honorable sénateur Pépin,

Que par dérogation à l'ordre adopté par le Sénat le jeudi 7 octobre 2004, le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système des soins de santé au Canada en octobre 2002 et les développements (la santé mentale et la maladie mentale), soit habilité à présenter son rapport final au plus tard le 30 juin 2006 et qu'il conserve tous les pouvoirs nécessaires pour diffuser ses conclusions jusqu'au 31 octobre 2006;

Que le Comité soit autorisé, nonobstant les pratiques habituelles, à déposer son rapport auprès du greffier du Sénat si le Sénat ne siège pas, et que ledit rapport soit réputé avoir été déposé au Sénat.

Après débat,

La motion, mise aux voix, est adoptée.

---

Extrait des *Journaux du Sénat* du mardi 25 avril 2006:

L'honorable sénateur Keon propose, appuyé par l'honorable sénateur Stratton,

Que le Comité sénatorial permanent des Affaires sociales, des sciences et de la technologie soit autorisé à examiner, pour en faire rapport, les questions qu'ont suscitées le dépôt de son rapport final sur le système de soins de santé au Canada en octobre 2002 et les développements subséquents. En particulier, le Comité doit être autorisé à examiner la santé mentale et la maladie mentale;

Que les mémoires reçus et les témoignages entendus sur l'étude de la santé mentale et des maladies mentales par le Comité durant les trente-septième et trente-huitième législatures soient déferés au Comité;

Que le Comité présente son rapport final au plus tard le 30 juin 2006 et qu'il conserve tous les pouvoirs nécessaires pour diffuser ses conclusions jusqu'au 30 septembre 2006, et

Que le Comité soit autorisé, nonobstant les pratiques habituelles, à déposer son rapport auprès du greffier du Sénat si le Sénat ne siège pas, et que ledit rapport soit réputé avoir été déposé au Sénat.

Paul C. Bélisle

*Greffier du Sénat*

Les sénateurs suivants ont participé à l'étude sur la santé mentale du Comité sénatorial permanent des affaires sociales, des sciences et de la technologie :

L'honorable Michael J. L. Kirby, président du Comité

L'honorable Wilbert Joseph Keon, vice-président du Comité

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Ethel M. Cochrane

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*Membres d'office du Comité :*

Les honorables sénateurs: Jack Austin P.C. ou (William Rompkey) et Noël A. Kinsella ou (Terrance Stratton)

*Autres sénateurs ayant participé de temps à autre à cette étude :*

Les honorables sénateurs Di Nino, Dyck, Johnson, Kinsella, Lynch-Staunton, Mercer, Milne, Murray, Pearson, St.Germain, Stratton and Tardif.



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---

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Il tient en particulier à exprimer sa profonde reconnaissance aux personnes suivantes :

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Le Dr Duncan Sinclair, ancien président de la Commission de restructuration des services de santé de l'Ontario, qui nous a généreusement fait profiter de son expérience, ne ménageant ni son temps ni ses conseils, et dont le support a été fortement apprécié par le Comité tout au long de cette étude.

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À tous et à toutes, nous tenons à exprimer nos sincères remerciements pour l'excellent travail accompli.

Depuis de nombreux mois, le Comité travaille de longues heures, épaulé par un grand nombre d'agents de la procédure, d'attachés de recherche, d'agents d'administration, de rédacteurs, de journalistes, d'interprètes, de traducteurs, de messagers, ainsi que d'employés des publications, de la télédiffusion, de l'imprimerie, des services techniques et des services logistiques, qui ont assuré le bon déroulement des travaux et la production des rapports du

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Dans son étude sur les services psychiatriques au Canada intitulée *Au service de l'esprit*, l'Association canadienne pour la santé mentale faisait le constat suivant :

Aucune autre affection, sauf peut-être la lèpre, n'a causé au patient autant de confusion, d'erreurs d'aiguillage et d'opprobre que la maladie mentale [...] Quelle que soit l'époque, les personnes atteintes ont été exclues, bannies de la société. Encore de nos jours, la maladie mentale est trop souvent considérée comme un crime à sanctionner, un péché à expier, un démon à exorciser, une honte à dissimuler, une tare à déplorer ou un problème d'assistance sociale à régler au moindre coût<sup>1</sup>. [traduction]

Ces propos datent de près d'un demi-siècle. Et pourtant, le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie a recueilli plus de deux mille témoignages, livrés par des personnes atteintes de maladie mentale et des membres de leurs familles, qui confirment que la situation n'a pas changé.

Pour les membres du Comité, il était douloureux d'entendre ces témoignages. Chacun de nous a été profondément troublé en écoutant et en lisant ces récits et, au fil des mois, nous avons ressenti la déchirure jusqu'au fond de notre âme.

Les membres du Comité ont été touchés en raison de leurs propres expériences. Notre groupe, comme tout groupe d'une douzaine de personnes, a vécu l'impact de la maladie mentale sur la famille : une belle-sœur aux prises avec la schizophrénie, un neveu qui s'est enlevé la vie, une fille qui a lutté contre l'anorexie pendant des années, une sœur qui a dû être hospitalisée à maintes reprises pour dépression grave; rares sont les familles qui ne sont pas affectées par la maladie mentale.

C'est en raison de ce vécu personnel que le rapport est devenu pour nous beaucoup plus qu'une simple étude de politiques : elle a pris l'allure d'un véritable apostolat.

Nous savons à quel point il est difficile d'améliorer la situation des personnes atteintes de maladie mentale. Nous savons qu'il sera encore plus difficile de modifier des attitudes profondément enracinées et d'atténuer l'opprobre et la discrimination. Le défi à relever est formidable : conduire chacune de ces personnes sur la voie du rétablissement.

Et, pourtant, nous sommes convaincus qu'il est désormais possible d'effectuer de réels changements. Nous avons parcouru le Canada et rencontré des politiciens, des hauts fonctionnaires, des fournisseurs de services de santé mentale et une multitude de simples citoyens qui veulent s'investir afin de démarginaliser les personnes aux prises avec la maladie mentale.

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<sup>1</sup> Association canadienne pour la santé mentale, (1963), *Au service de l'esprit : une étude des services psychiatriques au Canada*, Toronto, p. 1.

Nous invitons les lecteurs à travailler à nos côtés à la transformation des services offerts en santé mentale, en maladie mentale et en toxicomanie au Canada, de sorte que les personnes atteintes de maladie mentale puissent enfin passer *De l'ombre à la lumière*.

*J'espère que les Canadiens nous accueilleront au sein de la société en nous traitant comme des partenaires à part entière. Nous ne voulons pas être craints ou pris en pitié. N'oubliez pas que nous pourrions être vos mères et vos pères, vos sœurs et vos frères, vos amis, vos collègues de travail et vos enfants. Tendez-nous la main et voyagez avec nous sur la voie du rétablissement.*

Roy Muisse — 9 mai 2005 - Halifax<sup>2</sup>

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<sup>2</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47)





## PARTIE I

Le visage humain de la  
maladie mentale et de  
la toxicomanie

*J'ai dû implorer mon médecin traitant de me donner un rendez-vous avec un psychiatre. Je l'ai imploré, je l'ai supplié et voici ce qu'il m'a répondu : « Oui, eh bien, il traite 600 malades. Il se fait vieux et tu n'en as pas vraiment besoin. Contente-toi de prendre tes médicaments. »*

*[...]*

*Je suis inscrite à un programme à Merchant House; j'ai dû attendre six mois pour avoir une entrevue et être admise. Je suis heureuse de dire que je participe au programme, mais ma conseillère a recommandé que je fasse une thérapie de groupe; pour cela, je suis inscrite sur deux listes d'attente. Je suis la seizième sur une des listes et elle n'a pas voulu me dire quel était mon rang sur l'autre parce qu'elle est trop longue. Elle m'a dit que le programme était censé durer six mois, mais c'est en fait deux ans à cause de la longueur des listes d'attente.*

*[...] J'ai perdu des amis et des membres de ma famille parce qu'ils ont peur. Cette peur vient de leur ignorance et chaque jour, je dois faire face à la réalité des pensées suicidaires, des médicaments, de ma thérapie et des consultations psychiatriques. Ce n'est pas facile.*

*[...] je préférerais de loin avoir le cancer du sein plutôt qu'une maladie mentale. Je préférerais cela parce que je n'aurais pas à subir les préjugés<sup>3</sup>.*

L'histoire d'Helen est un exemple démoralisant du manque de soutien parmi les amis, les parents, les camarades de travail et les employeurs que connaissent tous les jours beaucoup de personnes ayant une maladie mentale. C'est aussi un exemple de la difficulté qu'ont trop souvent ces personnes à accéder aux services de santé mentale.

**J'ai perdu des amis et des membres de ma famille parce qu'ils ont peur. [...]**

**[...] Je préférerais de loin avoir le cancer du sein plutôt qu'une maladie mentale. Je préférerais cela parce que je n'aurais pas à subir les préjugés.**

**— Helen Forristall**

## 1.1 INTRODUCTION

Cette dernière année, le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie a reçu plus de 2 000 mémoires venant de tous les coins du Canada au sujet de la santé mentale, de la maladie mentale et de la toxicomanie. Des centaines de Canadiens avaient à raconter des histoires déchirantes qui ont éclairé le Comité sur la situation réelle du « système » canadien<sup>4</sup> de santé mentale, de maladie mentale et de toxicomanie.

<sup>3</sup> 14 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>4</sup> Comme l'indique le rapport provisoire du Comité (novembre 2004), le caractère très fragmenté de la prestation des services de santé mentale au Canada ne permet pas de dire qu'il existe vraiment un système cohérent et intégré de santé mentale. Dans le présent rapport, nous parlons de système pour indiquer simplement qu'une multiplicité de types de services et de soutiens, tant officiels qu'informels,

Grâce à deux consultations en ligne et à des audiences tenues dans l'ensemble des provinces et des territoires, le Comité a entendu le témoignage de ceux dont la vie est le plus directement touchée par le système de santé mentale du Canada : les personnes qui ont ou ont eu une maladie mentale ou une toxicomanie. Le présent chapitre a pour objet de présenter aux lecteurs quelques-unes des histoires que nous avons entendues, telles que nous les avons entendues. Nous espérons que ces récits toucheront les lecteurs autant qu'elles ont touché chacun des membres du Comité.

Les membres du Comité en sont venus à reconnaître une réalité : de profonds changements sont essentiels pour que les personnes ayant une maladie mentale reçoivent l'aide dont elles ont besoin et à laquelle elles ont droit. Nous espérons que les lecteurs du présent rapport parviendront à la même conclusion.

## 1.2 RAPPORTS AVEC LES SERVICES DE SANTÉ MENTALE ET DE LUTTE CONTRE LA TOXICOMANIE

Même si le Comité a entendu des personnes qui avaient réussi à trouver l'aide et les services dont elles avaient besoin, il a été attristé de constater qu'il y en avait beaucoup, beaucoup d'autres qui devaient constamment se battre afin d'obtenir les services nécessaires pour affronter la maladie et la toxicomanie et retrouver une vie normale. Le Comité a appris que ces gens devaient relever d'énormes défis et surmonter des obstacles extraordinaires dans leur recherche de la guérison : confusion et frustration pour déterminer comment et où trouver de l'aide; ignorance, manque de compassion et mauvaise attitude des professionnels de la santé; périodes d'attente interminables pour accéder aux services; honte et discrimination qui incitent beaucoup de malades à dissimuler leurs difficultés et souvent même à éviter de solliciter de l'aide pour les affronter.

### 1.2.1 Confusion et frustration

Tom, Paul et James ont parlé de la frustration que connaissent beaucoup de gens qui cherchent à trouver l'aide dont ils ont besoin.

*Je voulais appeler pour obtenir de l'aide. Je n'avais rien à manger et j'avais très froid. J'étais vraiment misérable. J'ai appelé à plusieurs reprises le service local de lutte contre la toxicomanie, mais je n'ai eu qu'un répondeur au bout du fil. Je n'avais pas un numéro de téléphone à donner pour qu'on me rappelle. Je raccrochais et je pleurais et pleurais. Ensuite, je suis devenu un vrai sans-abri, j'ai été jeté*

**...j'ai perdu tout espoir. Je ne crois plus que je guérirai un jour. Je ne crois pas que le gouvernement m'offrira jamais un vrai traitement pour m'aider à surmonter cette maladie.**

**[...]**

**En renonçant à tout espoir, je ne plonge pas encore plus profondément dans la dépression chaque fois que je suis rejeté ou qu'on m'enlève un autre espoir.**

**— James**

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sont offerts aux personnes ayant une maladie mentale ou une toxicomanie, aussi insuffisants que soient ces services et soutiens.

*en prison et j'ai essayé de me suicider. S'il y avait eu quelqu'un pour répondre à ce téléphone... —Tom*

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*Il est quasiment impossible d'avoir une idée globale de l'aide qu'on peut avoir et des moyens d'y accéder. Les renseignements disponibles sont fragmentaires et difficiles à comprendre pour une personne ordinaire. —Paul*

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*Bref, j'ai perdu tout espoir. Je ne crois plus que je guérirai un jour. Je ne crois pas que le gouvernement m'offrira jamais un vrai traitement pour m'aider à surmonter cette maladie.*

*Je vis dans une chambre, tout seul, comptant les heures. La seule raison pour laquelle je ne me suis pas suicidé, c'est que je voulais éviter de faire de la peine à mes parents.*

*Je n'ai jamais refusé un traitement. Je n'ai même pas refusé d'essayer une ou deux fois des médicaments expérimentaux. Toutefois, sans quelqu'un pour m'appuyer, sans un psychiatre compréhensif, je n'ai pas la force d'affronter le rejet constant des spécialistes qui, après avoir entendu mon histoire, croient qu'ils ne peuvent rien faire pour moi. En renonçant à tout espoir, je ne plonge pas encore plus profondément dans la dépression chaque fois que je suis rejeté ou qu'on m'enlève un autre espoir. —James*

### 1.2.2 Ignorance et manque de compassion

Deborah, Jennifer et Rafe ont, parmi d'autres, parlé au Comité de l'ignorance et du manque de compassion qu'ils ont constatés parmi les professionnels de la santé.

*Ceux qui travaillent dans le système de santé mentale doivent être compatissants. Ils doivent traiter les gens avec respect et dignité. Je constate que c'est toujours une lacune. —Deborah Jackman<sup>5</sup>*

**Pouvez-vous imaginer qu'une femme consulte un médecin à propos d'une bosse au sein, et que ce médecin lui réponde qu'il ne traite pas ce type de problème, mais qu'il peut donner un rendez-vous dans six à 12 mois avec un spécialiste? Pourtant cette situation est fréquente pour les personnes qui surmontent la gêne liée aux problèmes de santé mentale et décident de consulter leur médecin.**

**— Rafe Mair**

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<sup>5</sup> 14 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Je peux vous parler de mon expérience personnelle. J'ai vécu dans une aile psychiatrique, et ça a été l'une des expériences les plus traumatisantes de ma vie.*

*Si on plaçait dans un autre contexte les choses qui se passent dans une aile psychiatrique, on considérerait que c'est un désastre. Les personnes sont enfermées dans de petites pièces dont elles ne peuvent pas partir, elles sont attachées à un lit, on leur injecte des agents chimiques contre leur volonté : c'est vraiment une expérience traumatisante. On se fait dire que c'est correct, parce que ça se passe dans un hôpital. C'est vraiment une façon de déformer la réalité. — Jennifer Chambers<sup>6</sup>*

*Pouvez-vous imaginer qu'une femme consulte un médecin à propos d'une bosse au sein, et que ce médecin lui réponde qu'il ne traite pas ce type de problème, mais qu'il peut donner un rendez-vous dans six à 12 mois avec un spécialiste? Pourtant cette situation est fréquente pour les personnes qui surmontent la gêne liée aux problèmes de santé mentale et décident de consulter leur médecin. — Rafe Mair<sup>7</sup>*

### 1.2.3 Manque de services

Beaucoup de participants, dont Pat, Francesca, Susan et Raymond ont dit au Comité qu'à part la confusion et la frustration au sujet de l'accès aux services, il arrive souvent que les personnes ayant une maladie mentale ne trouvent tout simplement aucun service.

**Mais nous ne devrions pas nous demander ce qui est le mieux pour le personnel. Nous devrions nous demander comment ces patients prendront du mieux afin de pouvoir retourner à leur vie normale.**

**— Francesca Allan**

*Les seules ressources que nous ayons en abondance sont, encore une fois, de coûteux psychiatres, des ergothérapeutes, des infirmières et des travailleurs sociaux qui en sont réduits à distribuer des pilules et des seringues, de façon à garder les malades sortants dans une camisole de force chimique, pour rassurer le reste de la collectivité.*

*Si un client est déprimé et en colère en raison des contraintes qu'on lui impose, on augmente sa dose de médicaments. S'il a peur de son propriétaire ou s'il est incapable de dormir dans une pièce surpeuplée, on augmente sa dose de médicaments. S'il est affamé et agité par la pauvreté, on augmente sa dose de médicaments, et s'il lui reste suffisamment*

<sup>6</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>7</sup> 7 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/19evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/19evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*d'énergie pour se mettre en colère, la posologie veillera à ce que cette colère s'estompe. —Pat Capponi<sup>8</sup>*

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*L'autre problème grave vient de ce que les hôpitaux cherchent à simplifier l'administration. C'est plus facile si les patients sont médicamentés, parce qu'ils ne dérangent plus. Ils restent là à plonger leur regard vide dans le mur ou la télé. C'est sans doute mieux pour le personnel.*

*Mais nous ne devrions pas nous demander ce qui est le mieux pour le personnel. Nous devrions nous demander comment ces patients prendront du mieux afin de pouvoir retourner à leur vie normale. —Francesca Allan<sup>9</sup>*

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*Les statistiques prouvent que les médicaments seuls ne donnent pas des résultats aussi efficaces que lorsqu'ils sont jumelés à des séances de psychothérapie. D'autres types de thérapies ne sont pas accessibles à ceux et celles d'entre nous qui ont un revenu fixe ou un revenu insuffisant pour pouvoir couvrir les coûts parfois élevés liés à des thérapies faisant appel à des psychologues, des travailleurs sociaux et à des praticiens de médecine douce.*

**Notre régime provincial de santé couvre le coût des services psychiatriques, mais pas le coût des services psychologiques. Je dois payer sans pouvoir avoir recours à l'aide d'un régime d'assurance médicale privé. Ma famille survit avec un seul revenu.**

**— Susan Kilbridge-Roper**

*[...] Je retrouve petit à petit une certaine santé mentale, mais je ne pourrai jamais me rétablir sans l'aide d'un psychiatre et d'un psychologue. Notre régime provincial de santé couvre le coût des services psychiatriques, mais pas le coût des services psychologiques. Je dois payer sans pouvoir avoir recours à l'aide d'un régime d'assurance médicale privé. Ma famille survit avec un seul revenu... —Susan Kilbridge-Roper<sup>10</sup>*

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<sup>8</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>9</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>10</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*... ce dont les gens ont besoin, c'est d'un endroit sécuritaire et confortable, ouvert aux heures qui leur conviennent, qui répondent à leurs besoins, et d'avoir un sentiment de communauté, de manger ensemble, de se parler, de rire ensemble et de s'entraider. Malheureusement, ici en Ontario, cela ne constitue pas des heures facturables, donc nous n'obtenons pas le genre d'aide financière dont nous avons besoin, mais il s'agit d'un service tout aussi valable et tout aussi utile. —Raymond Cheng<sup>11</sup>*

### 1.3 QUE VEULENT CEUX ET CELLES QUI ONT UNE MALADIE MENTALE?

#### 1.3.1 Les déterminants sociaux de la santé mentale

Des personnes touchées par la maladie mentale ont parlé au Comité d'un certain nombre de services qu'elles croyaient nécessaires pour affronter et surmonter leurs troubles. Les services de soutien social — aide à l'emploi, logement décent, éducation et recherche, efforts personnels et groupes d'entraide — sont considérés comme les plus importants.

Pour des témoins comme Diana et Raymond, les déterminants sociaux de la santé mentale ont en général été négligés malgré leur importance dans la prévention et le traitement de la maladie mentale.

*[...] Le bien-être passe par la participation, l'autodétermination et l'estime de soi. —Diana Capponi<sup>12</sup>*

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*... la santé mentale fait partie intégrante du bien-être physique, social, spirituel et économique de chacun. On ne peut avoir espoir en l'avenir que si on est intimement convaincu que les inégalités présentes dans la société disparaîtront.*

*[...] mes amis vous ont entretenus éloquemment de ce que cela représente pour eux d'avoir un emploi, un endroit pour lequel on a un sentiment d'appartenance, un réseau social d'amis. J'espère que vous répondrez à cet appel collectif et que vous comprendrez que la guérison individuelle des malades mentaux est impossible quand on doit faire face aux conséquences de la pauvreté, de la stigmatisation et de la discrimination. —Raymond Cheng<sup>13</sup>*

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<sup>11</sup> 17 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>12</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>13</sup> 17 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

### 1.3.2 Aide à l'emploi

Karen, Joan et un autre participant qui a préféré garder l'anonymat ont expliqué la difficulté qu'ont les gens ayant une maladie mentale à trouver du travail.

*Dans mon propre cas, comme je n'ai rien caché de ma maladie, il m'a fallu des années pour trouver un emploi décent et stable. J'avais l'impression que les employeurs me considéraient comme un risque. Si j'avais survécu au cancer, au diabète ou à un taux élevé de cholestérol, je ne crois pas que j'aurais eu les mêmes difficultés. —Karen*

*Les gens sont terrorisés de perdre leur aide au revenu, parce que s'ils retournaient sur le marché du travail, ils devraient gagner plus de 50 000 \$ par année pour pouvoir continuer de payer leurs médicaments.*

**... la guérison individuelle des malades mentaux est impossible quand on doit faire face aux conséquences de la pauvreté, de la stigmatisation et de la discrimination.**

**— Raymond Cheng**

*Je connais quelqu'un qui doit payer 1 500 \$ par mois pour ses médicaments, ce qui est choquant, ce n'est pas que la personne prenne des médicaments aussi chers, mais plutôt le fait que les personnes sont prises dans ce genre de dilemme. Elles souhaitent travailler, mais savent pertinemment que leur compétence ne leur permet pas de faire suffisamment d'argent pour payer leurs médicaments. —Joan Edwards-Karmazyn<sup>14</sup>*

*Les modalités du Programme ontarien de soutien aux personnes handicapées sont discriminatoires pour les personnes ayant une maladie mentale qui veulent travailler. En effet, si elles gagnent plus de 160 \$ par mois, elles doivent restituer ce qu'elles ont reçu du Programme, ce qui les maintient à jamais au-dessous du seuil de la pauvreté. —Anonyme*

**Les gens sont terrorisés de perdre leur aide au revenu, parce que s'ils retournaient sur le marché du travail, ils devraient gagner plus de 50 000 \$ par année pour pouvoir continuer de payer leurs médicaments.**

**— Joan Edwards-Karmazyn**

### 1.3.3 Un logement décent et sûr

Katherine et Scott ont dit au Comité que les gens ayant une maladie mentale ont également de la difficulté à trouver un logement décent et sûr.

<sup>14</sup> 14 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Bonne chance si vous voulez trouver un logement décent et que les propriétaires apprennent que vous avez une maladie mentale.*  
—Katherine

*Il y a des quartiers de cette ville et de nombreux autres endroits au Canada qui sont remplis de maisons d'accueil du genre et où l'on trouve des gens dont la vie est simplement ponctuée par la prise régulière de médicaments. Beaucoup d'entre eux n'ont pas vraiment de but, parce que la société canadienne n'a pas reconnu leur valeur. Certains sont aux prises avec une pauvreté noire et habitent des logements tellement répugnants que même les plus forts d'entre nous, s'ils se retrouvaient dans de telles conditions, en perdraient la raison.* —Scott Simmie<sup>15</sup>

**Bonne chance si vous voulez trouver un logement décent et que les propriétaires apprennent que vous avez une maladie mentale.**

— Katherine

#### 1.3.4 Groupe d'entraide

Pour de nombreux témoins, les groupes d'entraide constituent l'un des services les plus importants à fournir pour favoriser le rétablissement des personnes ayant une maladie mentale. Susan, Joan, Jean-Pierre, un participant anonyme et Roy ont parlé au Comité de l'importance des groupes d'entraide.

**[...] j'ai appris plus de mes pairs que je n'en avais appris au cours des douze années précédentes au sein de ce que j'appelle le « système officiel de santé mentale ».**

**J'ai appris en écoutant d'autres personnes dire comment elles prenaient soin d'elles et ce qu'elles faisaient pour maintenir une bonne santé mentale. J'ai essayé certaines de leurs méthodes, et quelques-unes ont fonctionné. Je n'ai pas pris de médicaments depuis, et je n'ai reçu aucun traitement officiel de santé mentale depuis 2000.**

— Jean-Pierre Galipeault

*L'efficacité de l'effort autonome et des groupes de soutien dans le rétablissement a été très bien documentée. Mon expérience en qualité de membre et de dirigeante d'un tel groupe m'a apporté une connaissance intime des effets bienfaisants du partage des joies et des peines auxquelles nous sommes confrontés quotidiennement, du fait que nous avons des problèmes semblables.* —Susan Kilbridge-Roper<sup>16</sup>

<sup>15</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>16</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Pourquoi la prise en charge de soi? Les personnes qui interagissent avec leurs pairs au sein de groupes de prise en charge de soi adoptent une approche volontariste à la gestion de leurs problèmes et à la recherche de solutions.*

*L'accent est mis sur le bien-être et non pas sur la maladie, sur les aptitudes et non les incapacités, sur l'acceptation de ses limites plutôt que de vivre diminué à l'intérieur du carcan de ses limites, de se concentrer sur le début du processus de rétablissement au lieu de rester stagnant, prisonnier de sa détresse. Le but, c'est de retrouver l'énergie d'exercer de nouveau sa liberté de choix et de redonner au consommateur-survivant le goût d'exercer ses choix et de se sentir à nouveau vivant. —Joan Edwards-Karmazyn<sup>17</sup>*

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*J'ai appris le diagnostic il y a quelques années. On peut dire que bien des Canadiens souffrant d'une maladie mentale traitent cette maladie par des médicaments. J'ai passé presque douze ans à essayer de trouver le bon médicament.*

*Peut-être que je n'apprends pas vite, mais lorsque j'ai trouvé un groupe d'entraide, le déclic s'est fait.*

*[...] j'ai appris plus de mes pairs que je n'en avais appris au cours des douze années précédentes au sein de ce que j'appelle le « système officiel de santé mentale ».*

*J'ai appris en écoutant d'autres personnes dire comment elles prenaient soin d'elles et ce qu'elles faisaient pour maintenir une bonne santé mentale. J'ai essayé certaines de leurs méthodes, et quelques-unes ont fonctionné. Cette expérience en groupe m'a amené à élaborer un plan de guérison personnel, et, en 1996, j'ai cessé de prendre mes médicaments psychiatriques. En général, je ne le recommande pas, mais j'ai décidé de le faire parce que les effets secondaires à long terme m'inquiétaient. Je n'ai pas pris de médicaments depuis, et je n'ai reçu aucun traitement officiel de santé mentale depuis 2000. —Jean-Pierre Galipeault<sup>18</sup>*

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<sup>17</sup> 14 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>18</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Nous avons besoin de programmes pour donner aux gens des capacités et des moyens d'affronter les autres et de faire face au stress, à la colère, à la tristesse, etc. Les groupes d'entraide devraient toujours être là. On doit pouvoir assister à des réunions ou aller voir quelqu'un quand on en a besoin.*

*C'est vraiment très utile de pouvoir parler à quelqu'un qui comprend tous les tourments qu'on ressent et qui écoute sans porter un jugement. Cette personne peut également suggérer des choses qui ont marché pour elle dans des circonstances semblables et qu'on peut vouloir essayer soi-même. Il est extrêmement important de pouvoir aller dans un endroit sûr pour parler ouvertement de ce qu'on ressent. —Anonyme*

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*Je suis atteint d'une maladie mentale depuis près de 30 ans.*

*[...] J'ai reçu mon premier traitement psychiatrique dans les années 70. [...] en 1979, j'ai été hospitalisé pour la première fois pour « neurasthénie » ou ce que l'on appelle aujourd'hui « dépression nerveuse ». L'expérience a été horrible, et c'est un euphémisme. Cette dépression est survenue à une époque où les personnes atteintes d'une maladie mentale étaient très souvent sous médication excessive.*

*[...] J'ai survécu au cours des années 80. J'ai perdu mon entreprise, je me suis séparé de ma femme et je suis devenu une personne que je n'aimais pas vraiment, mais je refusais d'admettre que quelque chose n'allait pas...*

*Puis, vinrent les années 90. Je fus malade pendant presque toute cette décennie. J'ai fait deux tentatives de suicide et j'ai été bien proche d'en faire d'autres à de nombreuses autres occasions; j'ai même suivi une série de traitements par électrochocs...*

*À l'hôpital, j'ai été traité avec respect et amabilité, mais j'ai pu constater que tous les travailleurs étaient surmenés. À cette époque, je me suis renseigné moi-même sur la dépression et j'étais prêt à tout essayer pour aller mieux. Rien ne semblait être efficace...*

*J'ai appris grâce à des activités bénévoles que j'avais une aptitude naturelle pour discuter avec d'autres consommateurs de services de santé mentale et les écouter, et nous en avons apparemment tous tiré profit...*

*C'était un rêve que je ne pensais jamais pouvoir réaliser. Je suis aujourd'hui la preuve vivante que les rêves sont réalisables. En 2001, on*

*m'a offert un emploi au Consumer Initiative Centre, un programme de la Self-Help Connection, organisme fondé sur le pouvoir du soutien par les pairs. J'ai été engagé comme travailleur en entraide. —Roy Muise<sup>19</sup>*

## 1.4 STIGMATISATION ET DISCRIMINATION

Les histoires de stigmatisation et de discrimination que nous présentons dans ce chapitre ne font que donner une très vague idée des attitudes et des traitements injustes que connaissent tous les jours les personnes ayant une maladie mentale.

Beaucoup de participants ont parlé des circonstances dans lesquelles ils ont personnellement connu la stigmatisation et la discrimination dans tous les aspects de leur vie pour la seule raison qu'ils avaient une maladie mentale ou une toxicomanie.

### 1.4.1 Stigmatisation et discrimination dans le logement

Les tribulations de Linda et Phillip illustrent les difficultés que doivent affronter les personnes ayant une maladie mentale lorsqu'elles cherchent à trouver un logement décent et sûr.

*On ne peut pas savoir à quoi ça ressemble tant qu'on n'a pas vécu dans une pièce sombre et humide, sans fenêtres, sans climatisation ni chauffage, et sans aucun droit. À l'époque, je me trouvais chanceuse tout simplement parce que j'avais un toit et un lit. Je payais 550 \$ par mois pour ça, une pièce infestée de coquerelles et de souris, avec un lit dont les ressorts s'enfonçaient dans ma peau.*

**Ma vie est complètement transformée depuis que j'ai déménagé dans mon propre appartement. Ce n'est pas seulement un appartement. C'est ma maison. Je suis maintenant un membre productif de la société.**

**— Linda Chamberlain**

*C'était impossible de dormir, alors je changeais de matelas, mais le nouveau matelas était infesté de punaises. Ça vous semble horrible, mais en fait, c'est pire que tout ce que je pourrais dire. Je souffrais de dépression grave et j'étais fréquemment hospitalisée. J'ai vécu dans des endroits comme ceux-là pendant une bonne partie de ma vie.*

*[...] La première fois que je suis entrée dans le logement, qui comportait une chambre à coucher, je ne pouvais pas croire que c'était mon logement. Je ne croyais pas que je méritais de vivre dans un si bel endroit. Je croyais qu'on avait fait une erreur, et qu'on ne me laisserait pas là. Il y avait des fenêtres, elles s'ouvraient, je pouvais regarder dehors; oh! la lumière, le soleil. Je pouvais sentir l'odeur du gazon, et entendre les oiseaux. J'avais ma propre chambre à coucher, ma propre salle de bain. J'ai une cuisine complète, avec une cuisinière et un réfrigérateur. Je suis maintenant*

<sup>19</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*capable de préparer mes repas et je suis fière de pouvoir recevoir des invités.*

[...]

*Ma vie est complètement transformée depuis que j'ai déménagé dans mon propre appartement. Ce n'est pas seulement un appartement. C'est ma maison. Je suis maintenant un membre productif de la société. —Linda Chamberlain<sup>20</sup>*

*Quand on cherche à obtenir plus de logements avec services de soutien, nous devons souvent combattre le syndrome Pas dans ma cour, la stigmatisation de la maladie mentale et les règlements sur le zonage, qui traitent à part les logements avec services de soutien.*

**Comme tout le monde, les sans-abri et les malades mentaux ont le droit de vivre où ils veulent. Personne n'a le droit de nous empêcher de vivre dans un certain quartier. C'est un cas flagrant de discrimination et de violation des droits de la personne.**

**— Phillip Dufresne**

*Comme tout le monde, les sans-abri et les malades mentaux ont le droit de vivre où ils veulent. Personne n'a le droit de nous empêcher de vivre dans un certain quartier. C'est un cas flagrant de discrimination et de violation des droits de la personne.*

*Comment réagiriez-vous, et je m'adresse aux personnes qui se trouvent dans la salle, si quelqu'un vous disait : « Je ne veux pas que vous viviez dans mon quartier » ? Peu importe la raison pour laquelle on vous dirait cela, c'est mal. On n'a pas le droit d'empêcher des Noirs, des gais ou des Juifs de vivre dans un quartier ou un autre. On considère que c'est un crime haineux, et on ne devrait pas non plus en avoir le droit quand il s'agit de sans-abri ou de malades mentaux.*

*Si on nous réproche, ce n'est pas parce que nous avons fait quelque chose de mal, c'est à cause de la peur et de l'ignorance. —Phillip Dufresne<sup>21</sup>*

#### 1.4.2 Stigmatisation et discrimination dans les professions de la santé

Lisa, Sheila, Anita et Jeannie décrivent une stigmatisation et une discrimination d'un autre genre : celles que leur ont infligées des professionnels de la santé. Le Comité a toujours trouvé difficile de comprendre comment certains professionnels à qui des gens vulnérables s'adressent pour obtenir de l'aide peuvent si souvent les traiter aussi mal.

<sup>20</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>21</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*J'avais constamment l'impression, face à beaucoup des médecins à qui je me suis adressée dans le système de santé mentale, qu'ils étaient condescendants et cherchaient à me rabaisser. —Lisa*

*Dans le milieu des soins de santé, on n'est pas très à l'aise quand un des membres de la profession est atteint de troubles mentaux. On adopte l'attitude du « n'importe où, mais pas chez nous! ». Lorsqu'on se rend compte qu'il est atteint, on voudrait que le travailleur s'en aille et qu'il quitte son milieu de travail actuel. —Sheila Hayes Wallace<sup>22</sup>*

**Dans le milieu des soins de santé, on n'est pas très à l'aise quand un des membres de la profession est atteint de troubles mentaux.**

**— Sheila Hayes Wallace**

*Il m'est arrivé, tandis que j'étais au bord du suicide, d'avoir à attendre six heures dans une salle d'urgence pendant qu'on faisait passer avant moi d'autres personnes souffrant de troubles physiques.*

**Dans ma collectivité, le seul moyen d'obtenir rapidement des soins psychiatriques est de tenter de se suicider ou de commettre un crime. Cela, en soi, est un crime.**

**— Jeannie**

*La personne à la réception qui remplissait les papiers était au courant de mon état. Malgré cela, je devais attendre pendant qu'on s'occupait d'autres qui manifestaient des signes de détresse physique, avaient du sang qui coulait ou souffraient d'une fracture.*

*Quand j'arrivais finalement à parler à quelqu'un, c'était le plus souvent le psychiatre en formation, qui me demandait beaucoup de questions avant d'appeler le médecin de garde, puis le psychiatre de garde, qui venaient à leur tour poser les mêmes questions. Pour une personne dans un état d'anxiété extrême, cela est particulièrement frustrant et suffit souvent pour faire déborder le vase. Je suis alors traitée comme une malade violente. —Anita*

*Dans ma collectivité, le seul moyen d'obtenir rapidement des soins psychiatriques est de tenter de se suicider ou de commettre un crime. Cela, en soi, est un crime. —Jeannie*

<sup>22</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

### 1.4.3 Stigmatisation et discrimination lors du retour au travail

Les gens ayant une maladie mentale doivent affronter une autre forme de discrimination — qui, d'après beaucoup de ceux qui ont témoigné devant le Comité, est très courante dans le secteur de l'assurance — lorsqu'ils cherchent à trouver du travail ou à reprendre un emploi pour essayer de retrouver une vie normale.

Beaucoup de témoins, comme Scott et Darrell, ont parlé au Comité de la difficulté qu'ils ont eue à obtenir de l'assurance-vie, de l'assurance-invalidité ou de l'assurance médicale ou à présenter une demande d'indemnisation à la Commission provinciale des accidents du travail.

**(Une banque) m'a demandé de remplir un formulaire où l'on posait bien sûr la question : « Avez-vous déjà eu une maladie mentale? » Si vous cochez la case « Oui », on vous refuse l'assurance dans les banques canadiennes.**

**— Scott Simmie**

*Prenez mon cas, par exemple. Quand je suis revenu au travail, après m'être arrêté pour incapacité, j'ai voulu obtenir un prêt sur mon REER. Je suis allé à la banque, avec qui je faisais affaires depuis des années et le préposé m'a déclaré qu'il serait heureux de me donner un prêt. J'ai alors demandé une assurance sur le prêt, parce que je venais juste de revenir au travail et que je ne savais pas combien de temps j'allais y rester. On m'a demandé de remplir un formulaire où l'on posait bien sûr la question : « Avez-vous déjà eu une maladie mentale? » Si vous cochez la case « Oui », on vous refuse l'assurance dans les banques canadiennes.*  
— Scott Simmie<sup>23</sup>

*... on n'a pas la possibilité de surmonter sa maladie ou toute dépression antérieure. Si vous avez déjà consulté un psychologue ou un psychiatre au cours de votre vie, on utilisera cette information pour miner la demande d'indemnisation ou l'étendue de la demande au moment d'établir un diagnostic de SSPT ou de syndrome de la douleur chronique, comme dans mon cas.*

*Cet abus est si grave, et si lourd, que j'en suis venu à la conclusion qu'il n'y a aucune façon de se défendre — lorsque l'abus est intentionnel — sans recourir à la Charte des droits et libertés. Nous n'avons individuellement aucune capacité de faire respecter les droits que nous confère la Charte. Nous n'avons aucun pouvoir.* — Darrell Powell<sup>24</sup>

<sup>23</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>24</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

#### 1.4.4 Stigmatisation et discrimination dans la société

L'effet le plus préjudiciable attribué par les témoins à la stigmatisation et à la discrimination réside dans les attitudes de condescendance et de dénigrement manifestées partout dans la société à l'égard de la maladie mentale et de ceux qui en souffrent. Scott, Francesca, Ruth, Diana, Patricia, Kim et une participante qui a préféré garder l'anonymat ne sont que quelques-unes des nombreuses personnes qui ont parlé au Comité des souffrances que leur ont causées ces attitudes.

*Quand j'ai entrepris d'effectuer des recherches sur la santé mentale en 1998, je suis allé dans le plus gros hôpital psychiatrique de Toronto et, en arrivant, je suis tombé sur un panneau qui était censé indiquer : « Les chiens doivent être tenus en laisse ». Quelqu'un avait effacé le mot « les chiens » à la peinture et l'avait remplacé par « fous », et on lisait « Les fous doivent être gardés en laisse ». Chaque fois que j'allais à l'hôpital pour faire une entrevue, je vérifiais si ce panneau était encore là. Des patients l'avaient certainement vu, des médecins aussi et la population en général. Huit mois après avoir débuté mes recherches, quelqu'un a finalement daigné effacer à la peinture les mots offensants.*

**J'ai été conseillère, j'ai été enseignante suppléante, j'ai été éducatrice en garderie, j'ai travaillé dans un foyer pour femmes, mais une fois étiquetée « malade mentale », j'ai perdu toute crédibilité.**

**— Ruth Johnson**

*Passons maintenant à un scénario différent. Imaginez un panneau semblable sur le terrain d'une synagogue où l'on aurait remplacé le mot « chiens » par « juifs ». Les gens en auraient été révoltés. On aurait sans doute appelé la police, on aurait associé à juste titre cet acte honteux à un crime haineux et je peux vous garantir que ce panneau aurait été enlevé dès le lendemain. D'un autre côté, le panneau de l'hôpital, lui, est resté là très longtemps et Dieu sait depuis combien de temps il était là avant que quelqu'un le remarque. — Scott Simmie<sup>25</sup>*

*Les mots me manquent pour vous faire comprendre l'impact profond d'une étiquette psychiatrique sur la vie d'une personne. J'ai perdu mon emploi et j'ai perdu tout moyen d'en trouver un autre parce que j'ai été hospitalisée. — Francesca Allan<sup>26</sup>*

<sup>25</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>26</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*J'ai été conseillère, j'ai été enseignante suppléante, j'ai été éducatrice en garderie, j'ai travaillé dans un foyer pour femmes, mais une fois étiquetée « malade mentale », j'ai perdu toute crédibilité. —Ruth Johnson<sup>27</sup>*

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*Toutefois, lorsqu'une personne divulgue le fait qu'elle a éprouvé des problèmes de santé mentale, qu'elle ait affaire à un employeur, à l'exploitation d'une petite entreprise ou à une personne dans la rue, les attentes de ces personnes tombent immédiatement à zéro, et je n'exagère pas lorsque je dis cela. En réalité, on craint, franchement, que vous soyez violent. C'est la principale crainte, et on continue de la nourrir. —Diana Capponi<sup>28</sup>*

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*En fait, je suis bénévole depuis près de 20 ans, et je suis membre depuis trois ans du conseil d'administration du CTSM. Malgré ces longues années d'expérience et mes 33 ans à titre d'enseignante, lorsque je rencontre les gens et que je précise que je suis une ancienne toxicomane, la confiance diminue. C'est visible. C'est bien de faire partie du conseil d'administration. C'est bien d'être une enseignante à la retraite. C'est bien d'être une grand-mère, mais si je dis que je suis une ancienne toxicomane, on me fait moins confiance. —Patricia Commins<sup>29</sup>*

**Pourquoi faut-il, en plus de souffrir de cette maladie débilite, avoir à supporter le mépris de la société?**

**— Kim**

*Brisée. Solitaire. Désespérée. Honteuse. Rejetée. Isolée. Craintive. Sans appui. Perdue. Anxieuse. Peu crédible. Accablée. Embarrassée. Sombre. Peinée. Sans espoir. En décomposition.*

*Je suis une Canadienne de 31 ans. Je combats la dépression depuis l'adolescence. Les adjectifs ci-dessus sont ceux qui me viennent à l'esprit quand je pense à la vie que mènent au Canada les Canadiens et Canadiennes ayant une maladie mentale.*

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<sup>27</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>28</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>29</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Il est plutôt triste de penser que je souhaiterais avoir n'importe quelle autre maladie — je dis bien N'IMPORTE QUELLE AUTRE — plutôt qu'une maladie mentale. Il y a tellement de honte et d'incrédulité attachées à un diagnostic de maladie mentale. C'est en fait la preuve constante qu'on est vraiment malade. Pourquoi faut-il, en plus de souffrir de cette maladie débilitante, avoir à supporter le mépris de la société?*  
—Kim

*Je ne devrais ressentir ni honte ni crainte ni sentiment d'échec parce que j'ai une maladie mentale (trouble bipolaire). Je devrais pouvoir obtenir de l'aide et du soutien comme toute autre personne souffrant d'un trouble ou d'une maladie. Je ne devrais pas avoir à sensibiliser les gens qui n'ont pas jugé bon d'en apprendre davantage sur la maladie mentale, mais qui ont le pouvoir de prendre des décisions qui touchent à ma vie.*  
—Anonyme

#### 1.4.5 Suggestions pour mettre fin à la stigmatisation et à la discrimination

Ceux et celles qui ont parlé au Comité de leur expérience de la stigmatisation et de la discrimination ont également présenté des idées pour combattre ces attitudes et permettre à la société de se montrer plus accueillante envers les personnes qui ont une maladie mentale.

##### 1.4.5.1 Éducation et sensibilisation

C'est presque à l'unanimité que les participants ont parlé de la nécessité de sensibiliser les gens à la maladie mentale et à ceux qui en souffrent. Patricia et un participant anonyme ont expliqué comment la sensibilisation peut atténuer la stigmatisation et la discrimination.

*C'est seulement en changeant notre perception, en éliminant la tare sociale et en en apprenant davantage sur la maladie mentale que la société peut commencer à améliorer le traitement et les soins donnés aux gens qui souffrent de troubles mentaux.*

*Changer notre perception, c'est ouvrir la porte à l'espoir pour des milliers de Canadiens, c'est donner à cette question une plus grande visibilité auprès des responsables élus et une plus grande priorité lors de l'élaboration de nos politiques. La crainte de la maladie mentale réduit les ressources qui lui sont attribuées. —Anonyme*

**C'est seulement en changeant notre perception, en éliminant la tare sociale et en en apprenant davantage sur la maladie mentale que la société peut commencer à améliorer le traitement et les soins donnés aux gens qui souffrent de troubles mentaux.**

— Anonyme

*On peut s'informer des avantages et des gratifications du rétablissement auprès des personnes abstinentes qui sont disposées à en parler. C'est difficile. Il n'y a pas tellement de gens au Canada qui sont disposés à le faire, mais certains le sont quand même. C'est à nous de les trouver.*

*Des personnalités publiques et des citoyens ordinaires — des gens de tous horizons — pourraient vouloir parler de leur expérience ou ils pourraient la communiquer par écrit. Beaucoup de gens se refont une vie active en société. Comment s'y sont-ils pris? Qu'est-ce qui les a plus aidés? Qu'ont-ils à suggérer? —Patricia Commins<sup>30</sup>*

#### **1.4.5.2 Stigmatisation et discrimination dans les médias**

Pour Roman et un participant anonyme, parmi d'autres, les médias sont les mieux placés pour diffuser une information éclairée au sujet de la maladie mentale.

*L'industrie cinématographique s'est servie de la maladie mentale pour dramatiser ses productions. Elle a laissé entendre que le personnage peut souffrir ou souffre d'une maladie, que son comportement soit attribuable ou non à d'autres causes, affectives ou physiques. On doit lui faire prendre conscience des dommages que peuvent causer ces actions sur les personnes qui souffrent d'une maladie mentale et du mal qu'elle fait en stigmatisant ces personnes. —Roman Marshall<sup>31</sup>*

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*Une meilleure couverture médiatique de la réalité de la maladie mentale, par opposition à la recherche du sensationnel et à sa stigmatisation, serait très avantageuse. Il faut apprendre au public que, contrairement à ce qu'on voit à la télé, les gens ayant une maladie mentale sont non pas des fous dangereux, mais des amis, des voisins, des médecins, des avocats, etc. —Anonyme*

#### **1.4.5.3 Reconnaissance de la gravité de la maladie mentale**

De nombreux participants ont également souligné l'importance qu'il y a à accorder autant d'attention au traitement des maladies mentales qu'à celui des maladies physiques, aussi bien dans la profession médicale que dans l'ensemble de la société. Frank, Lisa et Sheila, ainsi que d'autres que nous avons cités plus haut, ont expliqué que la maladie mentale est souvent traitée différemment et fait l'objet de moins d'urgence et de moins d'importance que les affections physiques.

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<sup>30</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>31</sup> 31 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Depuis ce temps, j'ai eu l'occasion d'attendre à l'urgence du même hôpital avec des amis de mon groupe. Nous sommes retournés à la maison, désespérés. Malheureusement, nous ne sommes pas très prioritaires, et je ne sais pas pourquoi. Si du sang coulait le long de nos joues, nous deviendrions peut-être une priorité.*

*Je vais vous dire bien crûment : nous ne sommes pas importants. Il semble que nous n'ayons aucune importance aux yeux des professionnels de la santé. Je ne veux pas m'asseoir dans une autre salle d'urgence parce qu'un ami me dit « Je ne peux plus vivre, j'ai besoin d'aide ». Je le conduis à cet endroit et on nous demande de nous asseoir.*

**La maladie mentale est une maladie physique. Ce n'est pas une maladie qui atteint l'esprit des faibles et des médiocres. Tout comme le cancer, elle peut frapper n'importe qui.**

**Commençons donc à traiter la maladie mentale pour ce qu'elle est, une maladie dévastatrice.**

— Lisa

*Un petit tableau d'affichage indique que le prochain patient non prioritaire sera vu dans trois ou quatre heures. Je ne veux plus voir cela. Cette personne a besoin d'une chambre, a besoin de sécurité. Elle n'a peut-être pas besoin de médicaments ou de pareilles choses, mais elle a besoin de sécurité. Elle veut savoir que quelqu'un se préoccupe d'elle et elle ne doit pas se trouver dans une grande salle d'attente à l'urgence.*

*Nous voulons du respect et de la dignité. —Frank Dyck<sup>32</sup>*

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*Il faut commencer à traiter la maladie mentale tout autant comme une affection biologique que n'importe quelle maladie physique. Lorsqu'on dit qu'une personne est malade, on ne précise pas « physiquement malade ». Pourquoi donc faut-il dire « mentalement malade »? La maladie mentale est une maladie physique. Ce n'est pas une maladie qui atteint l'esprit des faibles et des médiocres. Tout comme le cancer, elle peut frapper n'importe qui.*

*Commençons donc à traiter la maladie mentale pour ce qu'elle est, une maladie dévastatrice. —Lisa*

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*Bien des sociétés et des entreprises se sont opposées à l'installation de rampes et d'ascenseurs. Pourtant, le monde des affaires ne s'est pas*

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<sup>32</sup> 2 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*écroulé et les personnes en chaise roulante ou celles qui ont un handicap auditif ou visuel ont maintenant la possibilité d'occuper un emploi.*

*Eh bien, il est maintenant essentiel de prendre des initiatives équivalentes pour les personnes qui ont des besoins particuliers en raison d'une maladie mentale. Il est essentiel que nous ayons nos propres « rampes », à défaut de trouver un meilleur terme. —Sheila Hayes Wallace<sup>33</sup>*

## 1.5 CONCLUSION

Tout le long du processus de consultation, le Comité a constamment entendu parler des difficultés que doivent affronter les personnes ayant une maladie mentale ou une toxicomanie, ainsi que de leur résistance et de leur faculté de récupération. Parmi les manifestations de frustration, de solitude et de souffrance, il y avait des récits fascinants de courage, d'espoir et de victoire sur l'adversité.

**Ne nous évitez pas lorsque nous prenons la parole. Notre maladie n'est pas contagieuse.**  
— **Sheila Hayes Wallace**

Des gens ayant une expérience personnelle de la maladie mentale et de la toxicomanie ont contribué, comme participants à part entière, à cette étude unique en son genre. Sans le courage qu'ils ont montré en racontant leur histoire au Comité, il aurait été impossible de produire ce rapport. Le Comité leur est très reconnaissant de la bonne volonté qu'ils ont manifestée en nous faisant part d'expériences personnelles intenses et souvent douloureuses dans le but d'améliorer les services de santé mentale et de lutte contre la toxicomanie du Canada, tant pour eux-mêmes que pour les autres.

*Ne nous évitez pas lorsque nous prenons la parole. Notre maladie n'est pas contagieuse. —Sheila Hayes Wallace<sup>34</sup>*

<sup>33</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>34</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).



## CHAPITRE 2: LE TÉMOIGNAGE DES FAMILLES

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### 2.1 INTRODUCTION

*Le pire, c'est de ne rien pouvoir faire, parce qu'on ne fait pas partie de la solution. —Darlene*

Parmi les nombreux mémoires reçus par le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, beaucoup venaient de personnes qui donnaient des soins non professionnels et non rémunérés à des membres de leur famille ayant une maladie mentale ou une toxicomanie. Comme Darlene, un grand nombre de ces personnes se sentent exclues et mises à l'écart par le système de santé mentale, de maladie mentale et de lutte contre la toxicomanie du Canada. Curieusement, ce sont ces mêmes membres de la famille qui donnent souvent le plus de soins et de soutien aux personnes ayant une maladie mentale.

Les membres de la famille ont parlé au Comité de leurs multiples frustrations : indifférence du système de santé mentale, incidence des soins donnés sur les autres membres de la famille et difficulté d'obtenir ce dont ils ont besoin pour donner les meilleurs soins possibles à leurs proches. Les membres du Comité ont été frappés non seulement par les effets de la maladie mentale sur la vie et la santé des aidants, mais aussi par le fait que leurs énormes efforts sont souvent méconnus et dépréciés par les professionnels et d'autres membres du système de santé mentale.

### 2.2 RAPPORT AVEC LES SERVICES DE SANTÉ MENTALE ET DE LUTTE CONTRE LA TOXICOMANIE

Mary, Donna, Doris, Bonita et Carolyn ont parlé au Comité de la difficulté qu'il y a à se battre pour un proche malmené par le système de santé mentale ou à qui le système tarde à donner les soins nécessaires. Elles nous ont rapporté comment des membres de leur famille ont été repoussés ou écartés lorsqu'ils ont cherché à obtenir de l'aide.

**Finalement, juste pour résumer, ce n'est pas le handicap qui est tragique. Ce qui est tragique, c'est la façon dont la société traite l'enfant et la famille qui sont confrontés au handicap.**

— Donna Huffman

*Notre fils s'est suicidé à 24 ans. S'il avait obtenu de bons soins, s'il avait eu un psychiatre qui se serait vraiment intéressé à son cas, il serait peut-être encore parmi nous aujourd'hui. —Mary*

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*Malheureusement, l'accès aux soins est une lutte quotidienne. Tous les services qu'on obtient pour notre enfant, en ce qui concerne un trouble*

*psychiatrique, est le résultat d'une lutte chèrement disputée, chèrement gagnée.*

*[...]*

*Finalement, juste pour résumer, ce n'est pas le handicap qui est tragique. Ce qui est tragique, c'est la façon dont la société traite l'enfant et la famille qui sont confrontés au handicap.*

*Nous pouvons nous occuper d'Alex. Jusqu'à maintenant, nous avons été en mesure de le faire avec le soutien limité que nous avons réussi à obtenir, et nous sommes très reconnaissants de ce soutien limité. Ce que nous ne pouvons pas faire, c'est nous battre constamment pour accéder à tous les services. —Donna Huffman<sup>35</sup>*

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*En septembre 1984, la propriétaire de mon fils à Toronto m'a appelée pour m'aviser qu'il avait été hospitalisé à l'aile psychiatrique après avoir tenté de sauter par la fenêtre de son appartement. J'étais convaincue que c'était le pire jour de ma vie, mais je me trompais. Ce n'était que le début d'une affreuse série noire qui allait culminer neuf ans plus tard, lorsqu'il a été déclaré non coupable d'homicide involontaire pour cause de troubles mentaux...*

*Après avoir appris ce qu'il avait fait, il s'est jeté contre les murs de sa cellule pendant trois jours, rongé par d'intenses remords. Pendant ce temps et pendant les quatre ans et demi qu'il a passés au Forensic Psychiatric Institute à Port Coquitlam, il n'a jamais eu de consultation psychologique, à l'exception de quelques séances de groupe animées par le très gentil pasteur de l'établissement. —Doris Ray<sup>36</sup>*

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*J'ai déjà conduit mon fils à l'urgence alors qu'il se trouvait dans une phase maniaque, et croyez-moi, c'est une expérience affreuse. Il se promène partout en traitant les gens de sorciers, il leur arrache les magazines des mains et il les effraie. Moi, je reste assise là à me ronger les sens en me demandant ce qu'il va bien pouvoir inventer.*

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<sup>35</sup> 1<sup>er</sup> juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evc-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evc-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>36</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*J'ai dû discuter ferme avec le médecin pour expliquer ce qui se passait. On a essayé de me dire qu'il avait pris de la drogue, ou qu'il était ceci ou cela.*

*Je leur ai dit, écoutez je sais très bien ce qu'il a. Il a une maladie mentale. Il a un dossier médical, ne pouvez-vous pas sortir son dossier? Non, c'était trop compliqué. Il faut vraiment faire tout un plat pour qu'on s'occupe de vous. Il faut vraiment que les choses changent dans les hôpitaux, ça c'est sûr. —Bonita Allen<sup>37</sup>*

*Je prends la parole à titre de mère d'une jeune femme qui, après huit ans aux prises avec un grave problème d'anorexie-boulimie, est décédée dans un système médical qui, essentiellement, ne se préoccupe pas de cette maladie mentale des plus mortelles.*

[...]

**Je prends la parole à titre de mère d'une jeune femme qui, après huit ans aux prises avec un grave problème d'anorexie-boulimie, est décédée dans un système médical qui, essentiellement, ne se préoccupe pas de cette maladie mentale des plus mortelles.**

**— Carolyn Mayeur**

*Au sein du système de soins de santé, Danielle a souvent été confrontée à l'attitude hostile des fournisseurs de traitements médicaux. On la traitait comme si son état découlait d'un désir d'adolescente de perdre du poids, d'une sorte de caprice. C'est faux. [...] Chaque bouchée, chaque pas étaient une véritable lutte pour elle.*

*De plus, elle n'a reçu aucun soin à l'égard de toute chose n'étant pas considérée comme liée au problème. Ses os étaient dans un état déplorable, mais elle n'était pas admissible aux médicaments pour les os, car ils étaient réservés aux 65 ans et plus.*

*[...] On ne lui a permis d'utiliser un lit fluidisé que lorsqu'on en a apporté un dans sa chambre d'hôpital, une heure avant qu'elle meure, pour soulager la douleur occasionnée par le dépérissement de ses os et de ses muscles, qui lui enlevaient toute amplitude de mouvement.*

[...]

*Une infirmière s'est mise à railler : « Eh bien, qu'est-ce que vous attendez de nous, exactement? » Et je lui ai répondu : « J'aimerais trouver une thérapie cognitivo-comportementale pour Danielle, ainsi qu'un psychiatre qui pourrait utiliser divers médicaments jusqu'à ce qu'il*

<sup>37</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*trouve celui qui permettra à Danielle de composer avec les graves pensées suicidaires qui la rongent cinq jours par mois. » L'infirmière m'a regardé, et a dit : « Vous rêvez en couleur. »*

*[...]*

*On a refusé à trois reprises d'admettre Danielle en salle d'urgence lorsqu'elle s'y est présentée, de peur de céder à ses idées suicidaires, parce qu'elle voulait vivre. Ce n'était pas pour avoir de l'attention. Ils ont ri de ses plans. [...] Un jour, cinq jours après avoir été renvoyée, elle a trouvé un plan efficace : la surdose. C'est moi qui l'ai trouvée.*

*Au cours des deux années qu'elle a passées à Toronto, à attendre son tour qui n'est jamais venu, dans une chambre louée à nos frais, elle se rendait à la salle d'urgence de l'hôpital et se tenait entre les portes, car, là, elle pouvait attendre, en toute sécurité, que ses idées suicidaires passent. Elle savait qu'elles passeraient, mais elle devait s'en assurer avant de partir. —Carolyn Mayeur<sup>38</sup>*

Le message que nous a transmis Carol était l'un des plus optimistes que nous ayons entendus.

*J'ai commencé à avoir des rapports avec les services de santé mentale lorsqu'on nous a dit que mon fils aîné Peter, alors âgé de 19 ans, était atteint de schizophrénie. Peter a maintenant 45 ans. Compte tenu de la gravité de sa maladie, je considère que son traitement a été en quelque sorte une réussite.*

*Depuis ce temps, Peter a eu des médicaments plus modernes. Il a pu obtenir un diplôme universitaire en mathématiques. Cela lui a pris 20 ans. Il travaille comme auxiliaire à l'enseignement au département de mathématiques de l'Université [...]. Il profite des services du Centre d'aide aux personnes handicapées de l'Université. Il poursuit en même temps des études de droit. Il travaille parfois comme gardien de sécurité et fait du bénévolat pour de nombreuses causes. Il vit avec une femme qui est également schizophrène. Il donne des conseils à d'autres gens qui connaissent les mêmes troubles ou des problèmes mentaux semblables. —Carol*

### 2.2.1 Manque d'information

Heather et Donna ont dit au Comité combien elles étaient frustrées par le fait de ne pas savoir à qui s'adresser quand un proche a besoin de soins. Beaucoup d'aidants familiaux ont

<sup>38</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

expliqué que la plus grande différence entre une maladie mentale et une maladie physique est que, dans le premier cas, il est tellement plus difficile d'obtenir des renseignements et de l'aide.

*Si votre enfant se casse un bras ou une jambe, vous savez où aller. Vous savez que, si vous y allez, quelqu'un vous aidera. Vous allez à l'urgence, et l'infirmière vous reçoit, le médecin vient vous voir, on vous fait passer des radiographies, et on met votre membre dans le plâtre, ou, dans le pire des cas, vous devez vous faire opérer, mais d'une façon ou de l'autre, vous obtenez de l'aide.*

**Lorsqu'on essaie de trouver de l'aide, on s'embarque dans une aventure frustrante, et on est seul. La plupart des gens effectuent beaucoup, beaucoup d'appels dans le but d'obtenir de l'aide. Lorsqu'on finit par trouver quelque chose qui donne espoir, on se retrouve sur une liste d'attente de dix mois. Pour reprendre l'analogie de la fracture, c'est comme si on se présentait à l'urgence avec une fracture et qu'on se faisait dire : « Oui, c'est vraiment fracturé, donc faites ce que vous pouvez pour vivre avec, et nous vous verrons dans dix mois ».**

**— Heather Dowling**

*[...] Si vous souffrez d'un trouble de l'alimentation, ça ne se passe pas comme ça. Vous ne savez pas où aller. Vos parents ignorent où demander de l'aide. Beaucoup de médecins et d'infirmières ne savent pas quoi faire pour vous. Bon nombre d'entre eux vous accusent d'être responsables de votre maladie. Cependant, vous êtes malade, vraiment malade.*

*Lorsqu'on essaie de trouver de l'aide, on s'embarque dans une aventure frustrante, et on est seul. La plupart des gens effectuent beaucoup, beaucoup d'appels dans le but d'obtenir de l'aide. Lorsqu'on finit par trouver quelque chose qui donne espoir, on se retrouve sur une liste d'attente de dix mois. Pour reprendre l'analogie de la fracture, c'est comme si on se présentait à l'urgence avec une fracture et qu'on se faisait dire : « Oui, c'est vraiment fracturé, donc faites ce que vous pouvez pour vivre avec, et nous vous verrons dans dix mois ».*

*[...] Tout ça semble ridicule. Personne ne ferait jamais ça, et personne ne devrait le faire. Toutefois, c'est ce qui se passe tout le temps en santé mentale, et c'est acceptable.*

*Lorsque ma fille avait 11 ans, on nous aurait traitées très différemment, ma fille et notre famille, si elle avait eu le cancer plutôt qu'un trouble de l'alimentation. [...] Lorsque son enfant souffre d'une maladie mentale, on vit la peur, le doute, on cherche des réponses. On essaie de s'adapter, on vit du stress et on subit des traumatismes affectifs comme si son enfant était gravement malade physiquement, mais on ne reçoit aucun soutien qu'on accorde habituellement à une personne qui est gravement malade physiquement.*

*Tout ce que je sais, pour ma part — et cela peut sembler horrible — mais je me suis souvent dis que j'aurais préféré que mon fils soit né aveugle, car, au moins, les gens auraient reconnu ce fait. Ils regarderaient mon fils, et diraient : « D'accord, nous savons ce que c'est, nous savons quel est le problème, nous savons de quels services il a besoin. » Et ce serait la fin de l'histoire, et je n'aurais pas à passer tout ce temps à défendre ses droits et à supplier les gens pour obtenir de l'aide. —Donna Huffman<sup>40</sup>*

**[...] Je me suis souvent dis que j'aurais préféré que mon fils soit né aveugle, car, au moins, les gens auraient reconnu ce fait. Ils regarderaient mon fils, et diraient : « D'accord, nous savons ce que c'est, nous savons quel est le problème, nous savons de quels services il a besoin. » Et ce serait la fin de l'histoire, et je n'aurais pas à passer tout ce temps à défendre ses droits et à supplier les gens pour obtenir de l'aide.**

**— Donna Huffman**

## 2.3 LES INCIDENCES SUR LA FAMILLE

Les aidants familiaux ont fait part au Comité de nombreux cas où les soins à donner à un proche ayant une maladie mentale ou une toxicomanie ont sérieusement ébranlé la famille, surtout à cause des effets physiques et affectifs de ces soins et du manque de reconnaissance et de soutien de leurs efforts.

**Et puis, quand vous vous apercevez qu'il n'existe quasiment pas de traitement pour votre enfant, la situation devient insoutenable.**

**— Phyllis Grant-Parker**

### 2.3.1 Effets physiques et affectifs

Carolyn, Joyce, Sheila, Lembi et Phyllis ont décrit certains des effets physiques et affectifs que connaissent les aidants familiaux.

*Dans notre famille, les trois d'entre nous qui restent avons commencé à souffrir de maladies chroniques en raison des huit ans de stress subi à vivre avec une personne qui, à la fin de sa vie, avait l'air de s'être échappée d'un camp de concentration, et du stress énorme et improductif*

<sup>39</sup> 31 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evaf.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evaf.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>40</sup> 1<sup>er</sup> juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evcf.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evcf.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*que supposait le fait de tenter d'obtenir des soins médicaux et de nous faire dire que nous exagérons. —Carolyn Mayeur<sup>41</sup>*

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*C'est ce que ma fille a dit. Pourquoi se préoccuperait-elle de prendre ses médicaments si c'est tout ce qu'on pouvait lui offrir? Si tout ce qu'on peut lui offrir est une vie passée à prendre des médicaments, sans amis, une vie d'assistée sociale sans avenir, à quoi ça sert de vivre? J'ai bien dû l'admettre. J'ai toujours pensé que si elle se suicidait, je pourrais lui pardonner, parce qu'elle serait en paix. —Jan House<sup>42</sup>*

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*C'est une chose terrible à dire, mais si ma fille se suicidait, je comprendrais. Ma fille m'a dit ceci : « Je ne sais pas ce que la vie a à m'apporter alors que j'entends des voix et que je ne peux pas la mener comme je le veux. Quel est le sens de ma vie? Je serais mieux si j'étais morte. » Nous avons eu à l'occasion des conversations intellectuelles au cours desquelles elle faisait preuve d'une grande perspicacité et pouvait tenir des raisonnements assez solides. Il est très difficile de trouver une raison de vivre dans ces circonstances. —Sheila Morrison<sup>43</sup>*

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*En réalité... mon mari doit présenter une nouvelle demande [de crédit d'impôt] chaque année. Je ne peux vous dire à quel point cette situation est stressante pour lui. Il doit consulter le médecin et s'assurer que le formulaire est dûment rempli afin qu'on ne pose pas de questions à ce sujet. C'est un événement annuel très stressant. C'est stressant pour lui et, comme on a parlé de contagion, c'est stressant pour moi. C'est comme si je suis également exposée à ce genre de stress, car, au cours de l'année, c'est tellement stressant de l'aider à maîtriser son stress que je ne sais pas où son problème se termine et où le mien commence. Au bout du compte, son problème devient le mien. —Lembi Buchanan<sup>44</sup>*

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<sup>41</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>42</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>43</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>44</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Les parents qui constatent les ravages de la psychose chez leur enfant et qui découvrent qu'il est atteint d'une maladie mentale grave, avec laquelle il devra vivre le reste de sa vie, sont dévastés, absolument dévastés. Et puis, quand vous vous apercevez qu'il n'existe quasiment pas de traitement pour votre enfant, la situation devient insoutenable. —Phyllis Grant-Parker<sup>45</sup>*

Mark a parlé par ailleurs des effets positifs sur la famille quand on arrive à obtenir des services efficaces pour un proche.

*Mon fils Kenny a souffert pendant 15 ans d'un trouble obsessionnel-compulsif grave. Il a maintenant réintégré la collectivité après des années de problèmes familiaux, à faire des séjours dans les hôpitaux, à consulter un psychiatre puis un autre, à chercher en vain vers qui se tourner. À cause de son trouble obsessionnel-compulsif, c'est une situation d'affrontement constant, et Kenny ne coopère pas du tout. Il vivait dans la rue, et nous étions toujours angoissés et pris de panique parce que nous ne savions pas où il était; était-il en sécurité? Il lui arrivait aussi de se présenter à mon studio, un itinérant, mon fils.*

*Nous cherchions désespérément. Nous avons enfin pu mettre mon fils en contact avec le système de services en santé mentale, qui fournissait des logements avec services de soutien. [...] Il n'existe pas de mots pour traduire les sentiments et le soulagement d'un parent qui voit enfin son fils ou sa fille fonctionner normalement et reprendre goût à la vie dans la collectivité et, surtout, dans sa famille. Cela me soulage de savoir que, lorsque nous disparaîtrons, notre enfant pourra toujours avoir un logement sûr et abordable. —Mark Shapiro<sup>46</sup>*

### 2.3.2 Manque de reconnaissance et de soutien

Même si les aidants familiaux peuvent passer des heures interminables à chercher infatigablement des services et des traitements et à défendre les intérêts de leur proche malade, leurs efforts sont souvent méconnus ou dépréciés. Joyce, Betty, Mike et deux participants anonymes ont fait part au Comité de leur frustration devant le manque de reconnaissance et de soutien des aidants familiaux.

**Je dirais même ceci : si les familles ne sont pas au cœur même de la conception des services destinés aux familles, cela ne fonctionnera pas. Nous sommes plutôt fatigués de fournir les services, de faire le travail et d'être négligés.**

**— Betty Miller**

<sup>45</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>46</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Quand on est aidant naturel, on est coincé également parce qu'on a peur de sortir de crainte de manquer un appel et que l'on n'a pas la confiance que l'on devrait avoir dans le système. Nous étions très souvent complètement désespérés et nous nous sentions abandonnés et ignorés. Je pense qu'un changement est absolument nécessaire à ce niveau. —Joyce Taylor<sup>47</sup>*

*Lorsque nous passerons à un paradigme qui accorde un rôle central réel aux clients, je vous prie de ne pas perdre de vue qui a dispensé le gros des soins liés à la santé mentale et à la toxicomanie. C'est nous, les familles et les amis, à raison de milliards d'heures de soins « informels » chaque année, ce qui permet au système de réaliser des milliards de dollars d'économie.*

*Ce que vous devez comprendre de cela, c'est que les familles n'ont ni soutien ni argent, ni attention.*

[...]

*Demandez aux familles ce qu'elles veulent, et elles vous le diront. Invitez-nous à participer à la création d'un système de prestations de services. Nous le ferons. Nous connaissons le système, et nous savons ce qui fonctionne et ce qui ne fonctionne pas. Nous avons des idées merveilleuses.*

*Je dirais même ceci : si les familles ne sont pas au cœur même de la conception des services destinés aux familles, cela ne fonctionnera pas. Nous sommes plutôt fatigués de fournir les services, de faire le travail et d'être négligés. —Betty Miller<sup>48</sup>*

**Beaucoup de membres du secteur de la santé mentale n'apprécient pas à sa juste valeur la contribution des membres de la famille au processus de rétablissement.**

**— Mike**

*Beaucoup de membres du secteur de la santé mentale n'apprécient pas à sa juste valeur la contribution des membres de la famille au processus de rétablissement. —Mike*

<sup>47</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>48</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Souvent, les membres de la famille sont le seul soutien des personnes ayant une maladie mentale, sans compter qu'ils doivent parfois aider des parents âgés tout en travaillant à plein temps. Les services de soutien aux aidants familiaux sont inexistantes. Des efforts particuliers doivent être déployés pour aider les membres de la famille des malades mentaux.*  
—Anonyme

*Les familles jouent un rôle vital dans le rétablissement du consommateur. Les aidants familiaux vivent le plus souvent avec le consommateur 24 heures sur 24, 7 jours par semaine, et ont donc une connaissance très précieuse de ses troubles mentaux. Ils fournissent le logement, le soutien social et financier, l'aide à se retrouver dans le système, etc. Ils constituent essentiellement la première ligne de soutien.*

*Ils ont un rôle unique dans le système, d'une part parce qu'ils aident le consommateur et, de l'autre, parce que leur connaissance du sujet leur permet de collaborer avec les professionnels. Il faut reconnaître leur rôle et les intégrer dans le système, non seulement au niveau du soutien, mais aussi au niveau de l'élaboration et de la mise en œuvre de la politique.*  
—Anonyme

## 2.4 QUE VEULENT LES AIDANTS FAMILIAUX?

Parce que les membres de la famille donnent souvent beaucoup de soins et d'aide sans être rémunérés ni reconnus, le Comité croit qu'il est essentiel d'écouter leurs suggestions. Les membres de la famille ont dit au Comité qu'ils ont besoin de diverses choses : plus d'information et d'éducation, un soutien du revenu, des services d'entraide, des services de relève, l'accès au plan d'intervention établi pour leur proche et le droit d'être traités avec respect lorsqu'ils discutent avec les médecins et d'autres de la façon dont le plan doit être réalisé et des personnes qui seront chargées de sa mise en œuvre.

**Les médecins m'ont appris en 1997 que mon fils était schizophrène. Ils l'ont ensuite renvoyé à la maison après trois jours à l'hôpital. Je n'avais aucune idée de ce que je devais faire. L'hôpital n'a fourni aucun renseignement. Il n'y a pas eu un appel ou une réunion de suivi. On m'a tout simplement dit que la Société locale de la schizophrénie pourrait avoir de la documentation à lire.**

— Anonyme

### 2.4.1 Information et éducation

Darlene et un participant qui a préféré garder l'anonymat ont parlé de la nécessité de donner plus d'information et d'éducation sur l'état de leur proche et sur la façon de l'aider.

*Quand une personne sur 100 est schizophrène, est-ce trop demander que de nous permettre de comprendre de quoi il s'agit? —Darlene*

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*Les médecins m'ont appris en 1997 que mon fils était schizophrène. Ils l'ont ensuite renvoyé à la maison après trois jours à l'hôpital. Je n'avais aucune idée de ce que je devais faire. L'hôpital n'a fourni aucun renseignement. Il n'y a pas eu un appel ou une réunion de suivi. On m'a tout simplement dit que la Société locale de la schizophrénie pourrait avoir de la documentation à lire. —Anonyme*

## 2.4.2 Soutien du revenu

Joan, Phyllis, Norrah et une participante anonyme ont parlé au Comité des difficultés financières que connaissent les membres de la famille d'une personne ayant une maladie mentale, lorsque celle-ci ne dispose d'aucun soutien du revenu.

**Il faut prendre en considération le fardeau financier que la maladie mentale impose aux familles. Les prestations d'invalidité accordées aux personnes atteintes de maladies mentales sont ridicules et la plupart des familles doivent y aller de leur poche pour combler des besoins de base comme de nouvelles chaussures, des soins dentaires, des articles liés aux soins de santé et de l'argent de poche.**

— Joan Nazif

*Il faut prendre en considération le fardeau financier que la maladie mentale impose aux familles. Les prestations d'invalidité accordées aux personnes atteintes de maladies mentales sont ridicules et la plupart des familles doivent y aller de leur poche pour combler des besoins de base comme de nouvelles chaussures, des soins dentaires, des articles liés aux soins de santé et de l'argent de poche. —Joan Nazif<sup>49</sup>*

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*... si nous avons eu de la chance de pouvoir accéder à ce genre de soutien, cela n'a pas été sans un coût énorme pour notre famille. Pour aller voir notre fils, nous devons conduire cinq heures à partir d'Ottawa. Le fait de le savoir malade et aussi loin de nous a eu de formidables répercussions émotives.*

*Dans les 14 mois qu'il a passé là-bas, nous avons parcouru 49 000 kilomètres, perdu la moitié de notre revenu familial, fermé une entreprise familiale et dépensé 29 000 \$ de notre poche. —Phyllis Grant-Parker<sup>50</sup>*

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<sup>49</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>50</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*La plupart des familles que je connais dans ma province connaissent des souffrances qui vont au-delà de ce que vous pourriez imaginer. Ils vendent leur maison, s'ils en ont une à vendre.*

*Je parlerai de ma propre situation. Je n'ai rien. Je serai pauvre toute ma vie. [...] Je ne serai jamais propriétaire d'une maison, d'une voiture digne de ce nom. Je ne serai peut-être même jamais capable de conserver un emploi décent, en raison du handicap de mon fils. —Norrah Whitney<sup>51</sup>*

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*J'ai un enfant atteint d'autisme, de THADA et de diverses autres affections. S'il a besoin d'une intervention chirurgicale pour lui sauver la vie, je peux l'obtenir en six heures ou moins.*

*Je n'ai accès à aucun traitement pouvant l'aider à devenir un membre productif de la société, à moins de trouver moi-même ce traitement. Toutefois, si j'acceptais de le bourrer de médicaments et de le laisser s'asseoir dans un coin, la province ne verrait aucun inconvénient à payer la facture. —Anonyme*

### 2.4.3 Service d'entraide

George nous a expliqué à quel point les services d'entraide sont importants pour les aidants familiaux, qui veulent parler de leurs craintes et de leurs frustrations à d'autres qui ont connu des expériences semblables, et apprendre d'eux comment affronter les problèmes.

*Nous essayons de leur faire comprendre qu'ils ne sont pas seuls dans toute cette aventure; ils peuvent compter sur l'amour et le soutien de toutes les personnes qui participent aux réunions, qui peuvent les aider à vivre leur douleur. J'ai vu des gens venir pour la première fois à une réunion et être tellement anéantis qu'ils ne pouvaient pas parler, et, des mois plus tard, j'ai vu ces mêmes personnes rire pour la première fois sans craindre de se sentir coupables ou d'avoir honte. —George Tomie<sup>52</sup>*

### 2.4.4 Service de relève

Betty et Annette ont expliqué au Comité l'importance d'un répit, d'une relève pour les aidants familiaux. De nombreux participants ont parlé de la difficulté qu'il y a à trouver des personnes fiables et compétentes à qui laisser la charge des soins à donner aux proches malades.

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<sup>51</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evaf.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evaf.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>52</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evbf.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evbf.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Les familles sont épuisées. Nous avons besoin d'aide. Nous vieillissons, et nous avons peur que nos proches soient laissés à eux-mêmes, dans la rue; et la rue existe dans les collectivités tant rurales qu'urbaines.*

*Les familles ont leurs propres peurs légitimes et besoins distincts. [...] Peut-être avons-nous seulement besoin qu'une personne prenne une heure de son temps pour nous aider à évaluer les choix qui s'offrent à nous. Il faut comprendre que nous sommes un peu fatigués, nous avons besoin de nous reposer. Quelqu'un pourrait peut-être prendre le relais pour quelque temps, nous donner une chance de respirer. —Betty Miller<sup>53</sup>*

**Les familles sont épuisées. Nous avons besoin d'aide. Nous vieillissons, et nous avons peur que nos proches soient laissés à eux-mêmes, dans la rue; et la rue existe dans les collectivités tant rurales qu'urbaines.**  
— Betty Miller

*Les familles ont besoin de services de relève. Elles ont besoin qu'on leur montre que le fait de ne pas être capable de donner des soins n'est pas la même chose de ne plus vouloir s'occuper d'un proche. Elles ont besoin de savoir qu'il y a un endroit où aller quand elles n'ont plus la force de continuer sans répit.*  
—Annette

**Les familles ont besoin de services de relève. Elles ont besoin qu'on leur montre que le fait de ne pas être capable de donner des soins n'est pas la même chose de ne plus vouloir s'occuper d'un proche. Elles ont besoin de savoir qu'il y a un endroit où aller quand elles n'ont plus la force de continuer sans répit.**  
— Annette

## 2.4.5 Accès aux renseignements personnels sur la santé

Un grand nombre de répondants ont souligné que l'accès aux renseignements concernant les soins donnés à leurs proches constituait, peut-être, l'aspect le plus important du traitement d'une maladie mentale ou d'une toxicomanie.

Brenda, Ruth, Phyllis et une répondante qui a préféré garder l'anonymat ont parlé du sentiment d'impuissance qu'elles ressentaient lorsqu'on refusait de leur donner accès à l'information relative au traitement d'un être cher. Et, pis encore, les professionnels de la santé à qui elles voulaient communiquer des renseignements importants concernant leur proche refusaient souvent de les écouter ou écartaient leurs arguments. Leur exclusion était aggravée par l'application de lois conçues pour protéger les droits individuels, mais qui, en cas de maladie mentale, risquent de porter un grave préjudice aussi bien à la personne en cause qu'à d'autres.

**La maladie mentale accable terriblement les membres de la famille. Ceux-ci ont besoin d'information, d'éducation et de soutien. Ce n'est que lorsque c'est absolument nécessaire pour le bien du client qu'on devrait exclure les membres de la famille du processus de traitement.**  
— Ruth Minaker

<sup>53</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*J'ai un fils de 25 ans qui est atteint de schizophrénie paranoïaque. Quand il prend ses médicaments, il a l'impression d'être guéri, ce qui l'amène à cesser de les prendre. Ses symptômes s'aggravent alors.*

*À cause des lois, on ne peut pas le forcer à prendre ses médicaments. Il doit alors être hospitalisé. Un défenseur des droits va ensuite le voir avec un formulaire et lui demande s'il veut rester. Bien sûr, il dit non.*

*Il a maintenant 25 ans. Il entend sans cesse des voix dans sa tête, et elles sont de plus en plus fortes. Son délire est de plus en plus violent. Il croit fermement qu'il peut vivre éternellement s'il boit du sang humain (parce que Dieu a dit de boire son sang) et que s'il meurt, il ressusciterait. Je vous assure que moi-même, les autres membres de la famille, son agent de probation et ses deux psychiatres sommes sûrs et certains qu'à défaut d'un traitement médical, mon fils finira par se tuer ou par tuer quelqu'un d'autre.*

*Il prend des médicaments sans ordonnance, comme c'est courant parmi ceux qui souffrent de cette maladie, pour faire cesser la vingtaine de voix perçantes qu'il entend dans sa tête.*

*Comme mère, je suis incapable d'aider mon fils qui a si désespérément besoin d'un traitement parce qu'il est LE SEUL qui puisse prendre la décision. Toutes les portes sont fermées pour ceux qui l'aiment le plus, c'est-à-dire les membres de sa famille. Nous devons rester là à observer pendant qu'il se transforme en une personne que nous ne connaissons plus et dont nous avons maintenant très peur.*

*Oui... c'est la pire expérience de la vie. Faire face à la loi qui nous enlève le droit d'aider une personne qui nous est chère.*

*Je crois que si un membre de la famille prouve à plusieurs reprises, si, comme dans notre cas, ses médecins disent qu'il est dangereux pour lui-même et les autres et ne peut pas fonctionner sans aide, alors, un parent doit pouvoir intervenir en son nom pour lui faire prendre ses médicaments et pour veiller à ce que ses besoins médicaux soient satisfaits.*

*En ce moment, notre fils est en prison parce qu'il représente une menace pour notre vie. Croyons-nous qu'il donnera suite à ses menaces? Oui, nous le croyons, de même que ses médecins, son agent de probation et la police. Vous devez comprendre que lorsque qu'un schizophrène paranoïaque ne prend pas ses médicaments, il délire, et ses parents et amis ne sont pour lui qu'autant de gens qui veulent le tuer.*

*Mon fils mérite de recevoir des traitements pour sa maladie mentale. Toutefois, tant que la loi restera telle quelle, les autorités ne feront qu'attendre qu'il mette ses menaces à exécution. Ensuite, elles diront : pourquoi personne n'a prévu que cela se passerait ainsi?*

*À mon avis, la façon la plus simple de nous faciliter les choses, c'est de nous permettre d'aider notre fils à se rétablir. Déliez-nous les mains, entendez notre appel, rendez-nous notre fils.*

*N'est-il pas suffisant qu'il soit malade? Fait-il en plus le punir pour sa maladie?*

*Mon plus grand souci, c'est que, comme mère d'un jeune homme que j'aime tant, je ne puisse rien faire pour l'aider. Nous sommes obligés de l'observer pendant que son état s'aggrave de jour en jour. Nous sommes obligés de regarder pendant qu'il se débat dans le système de justice pénale sans vraiment comprendre ce qu'il a fait de mal. Il n'a rien fait d'autre que ce que les voix dans sa tête lui ont dit de faire. Il n'a agi que sous l'effet du désespoir. Il avait faim et avait besoin de manger, il avait peur et luttait pour sa vie. Tuer ou être tué.*

*Nous savons, quand il nous appelle maman et papa, qu'il sait qui nous sommes. Mais quand il nous appelle par notre prénom, nous savons qu'il nous prend pour des ennemis. Depuis quelques années, nous avons une serrure sur la porte de notre chambre. —Brenda Valcheff*

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*La maladie mentale accable terriblement les membres de la famille. Ceux-ci ont besoin d'information, d'éducation et de soutien. Ce n'est que lorsque c'est absolument nécessaire pour le bien du client qu'on devrait exclure les membres de la famille du processus de traitement.*

*[...] Longtemps après que l'équipe de traitement a dispensé ses services, la plupart du temps, la famille est toujours dans la vie du client. —Ruth Minaker<sup>54</sup>*

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*Eh bien, j'estime qu'il est essentiel que les familles participent aux soins parce qu'elles sont le point de référence en ce qui concerne leurs membres. Elles connaissaient la personne avant que son comportement ne soit modifié par la maladie et elles sont le baromètre qui indique à quel point*

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<sup>54</sup> 31 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*le traitement donne des résultats. L'équipe médicale, elle, ne connaît que le malade.*

*Ainsi, les familles sont le point de référence parce que la véritable guérison consiste à ramener le malade à l'état dans lequel il était avant, ou du moins le plus près possible de cet état. Dès lors, il faut que les parents et les familles soient intégrés dans les équipes soignantes... — Phyllis Grant-Parker<sup>55</sup>*

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*J'ai un fils qui a une maladie mentale. Il a maintenant près de 40 ans. Nous avons dû le soigner. Nous avons dû le surveiller étroitement à plusieurs reprises lorsque nous avons l'impression qu'il voulait se suicider. Nous avons souvent dû l'emmener à la salle d'urgence de l'hôpital. Nous avons veillé à ce qu'il aille à ses rendez-vous. Nous l'avons appuyé affectivement, physiquement, financièrement. Mais quand c'est le moment de donner notre avis sur son traitement psychiatrique, on ne nous écoute même pas.*

*Notre fils peut raconter toutes sortes de mensonges à son médecin sans que nous puissions intervenir parce qu'il est adulte. Les médecins doivent parler aux membres de la famille et à ceux qui soignent les malades pour s'assurer que les renseignements qu'ils tiennent du consommateur sont exacts. — Anonyme*

## 2.5 CONCLUSION

Les membres de la famille qui donnent des soins et du soutien à des proches ayant une maladie mentale ou une toxicomanie doivent relever un double défi. D'abord, ils doivent souffrir avec leur proche pendant qu'il affronte ses difficultés quotidiennes et utiliser des ressources personnelles limitées pour les atténuer. Ensuite, ils doivent faire face à un système de santé mentale qui les empêche souvent de participer aux processus de collecte d'information et de décision tout en les laissant jouer le rôle de filet de sécurité offrant des soins illimités sans rémunération et remédiant aux lacunes du prétendu système.

**Les titulaires de charges publiques doivent-ils perdre eux-mêmes un enfant pour comprendre à quel point la situation de la santé mentale est désespérée au Canada? Il semble malheureusement que cela n'a vraiment de l'importance que pour les personnes qui ont vécu elles-mêmes ces circonstances.**

**— Ginny**

Les membres de la famille qui donnent des soins et du soutien à des proches ayant une maladie mentale ont un point de vue très particulier sur le système de santé mentale et sa

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<sup>55</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

réforme. Ils ont montré au Comité que, malgré leur frustration et leur fatigue, ils continueront à rechercher de l'aide pour leur proche et l'offriront eux-mêmes si leurs recherches sont vaines. Le Comité reconnaît leur contribution à l'étude. Les histoires qu'ils ont racontées sont pertinentes : nous devons les écouter et donner suite à leurs recommandations.

*Les titulaires de charges publiques doivent-ils perdre eux-mêmes un enfant pour comprendre à quel point la situation de la santé mentale est désespérée au Canada? Il semble malheureusement que cela n'a vraiment de l'importance que pour les personnes qui ont vécu elles-mêmes ces circonstances. —Ginny*





## PARTIE II

Aperçu



*Étant donné qu'un modèle a tendance à façonner notre perception des circonstances, il influence considérablement la gamme des services que nous cherchons à offrir et la manière de le faire, que ce soit en santé mentale ou en santé physique.<sup>56</sup>*

Après deux ans et demi d'étude du « système » de santé mentale et de toxicomanie au Canada, le Comité est encore frappé par le nombre de questions clés sur ce système qui ne peuvent pas engendrer de réponses faciles. Elles vont de questions factuelles (par ex. combien dépense-t-on annuellement dans chaque secteur de compétence pour les services de santé mentale et les soutiens?) à des questions fondamentales d'ordre philosophique, médicale et scientifique ayant trait à la nature des maladies mentales.

Le Comité a entendu de nombreux points de vue différents sur toute la gamme des questions, tous débattus avec passion, intégrité et éloquence. Les deux chapitres précédents illustrent la richesse de ces témoignages.

Des progrès importants ont été marqués au cours des dernières années dans la mise au point de nouveaux médicaments et de nouvelles méthodes de traitement des maladies mentales. De plus, les personnes atteintes de maladie mentale et leurs familles se font de plus en plus entendre et réclament à juste titre de participer à la prise de décisions les concernant. Il reste cependant encore beaucoup à faire. Voilà pourquoi, dans les rapports documentaires publiés en novembre 2004, le Comité a affirmé clairement que le maintien du statu quo n'est pas une option acceptable au Canada à propos de la santé mentale, de la maladie mentale et de la toxicomanie.

Ce qu'il faut, de l'avis du Comité, c'est un véritable système centré sur les personnes ayant une maladie mentale, en ciblant nettement leur capacité de rétablissement.

### 3.1 INTRODUCTION

#### 3.1.1 Limites du présent rapport à l'égard des toxicomanies

Le Comité estime qu'il est nécessaire de reconnaître dès le départ un élément qui sautera vite aux yeux du lecteur du présent rapport. Le Comité n'a pas été en mesure de prêter autant d'attention qu'il le prévoyait aux problèmes de toxicomanie lorsqu'il a entamé son étude de « la santé mentale, la maladie mentale et la toxicomanie ». Le présent rapport se concentre donc principalement sur les problèmes de santé mentale.

Il existe évidemment de nombreux chevauchements entre les problèmes de santé mentale et de toxicomanie, le fait de connaître à la fois des troubles de santé mentale et des

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<sup>56</sup> Participant anonyme, seconde consultation électronique

toxicomanies n'étant pas le moindre. Il est assez courant pour des gens de vivre avec les deux. Des recherches ont révélé que 30 p. cent des personnes chez lesquelles on a diagnostiqué une maladie mentale connaîtront également des problèmes de toxicomanie durant leur vie et que 37 p. cent des alcooliques (53 p. cent des personnes ayant une toxicomanie autre que l'alcoolisme) vivent également avec une maladie mentale<sup>57</sup>.

La relation entre les services concernant la maladie mentale (comme le traitement de la dépression, des troubles anxieux et des troubles schizophréniques) et les services concernant la toxicomanie (incluant le traitement de consommation d'alcool problématique, les services de gestion du sevrage, le traitement d'entretien à la méthadone pour la toxicomanie opiacée et les programmes d'échange de seringues) a fait l'objet de maints débats et de maintes discussions au Canada. Au cours des décennies précédentes, les services concernant ces deux types de troubles étaient administrés séparément; ils ont développé des philosophies de traitement divergentes, utilisé une terminologie différente et constitué des « cultures » différentes qui entraient souvent en conflit.

Le « choc culturel » entre les services de santé mentale et ceux de toxicomanie a créé de graves problèmes pour les clients, en particulier pour ceux atteints de troubles concomitants. Parce que les approches en matière de traitement sont contradictoires, les clients ont souvent reçu des renseignements et des conseils déroutants et incohérents. Ils ont couramment été exclus des services concernant la santé mentale s'ils avouaient des problèmes de toxicomanie et des programmes de traitement de la toxicomanie, s'ils avouaient utiliser des médicaments antidépresseurs.

À cause de l'importance des problèmes de toxicomanie en général, et de ce chevauchement en particulier, le Comité a consacré un chapitre du présent rapport aux problèmes de toxicomanie et s'est efforcé d'aborder les sujets communs de préoccupation à divers points dans tout le rapport. En outre, au Chapitre 16 le Comité formule une importante recommandation : que le gouvernement fédéral injecte 50 millions de dollars de plus par année dans les programmes axés sur les troubles concomitants.

Malgré tout cela, le Comité est profondément conscient des limites du présent rapport en ce qui concerne les toxicomanies. Il ne fait qu'effleurer la surface de nombreux problèmes de toxicomanie qui méritent un examen plus approfondi. Dans de nombreux cas, le Comité a également été incapable d'examiner complètement les similitudes et les différences des approches dans les domaines de la santé mentale et de la toxicomanie. Il ne serait pas judicieux pour le Comité de supposer que les conclusions auxquelles il est arrivé après avoir examiné attentivement les témoignages portant sur la santé mentale s'appliquent forcément aux problèmes de toxicomanie. Certains peuvent s'appliquer, mais le Comité a essayé d'éviter toutes les hypothèses gratuites à cet égard.

### **3.1.2 Quelques questions de « langage »**

Le langage utilisé pour parler d'un problème, et les modèles employés pour le comprendre, influe beaucoup sur la nature des politiques que l'on favorise ou que l'on avalise par la suite.

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<sup>57</sup> W. Skinner, C. O'Grady, C. Bartha et C. Parker, (2004), « Concurrent substance use and mental health disorders: An information guide », Toronto : Centre for Addiction and Mental Health.

Cette assertion ne semble plus vraie nulle part ailleurs que dans le domaine de la santé mentale, de la maladie mentale et de la toxicomanie.

Le présent rapport traite de la santé mentale, de la maladie mentale et de la toxicomanie. Par conséquent, de quelle façon devrait-il désigner les personnes les plus directement touchées par les maladies mentales et les toxicomanies? Comme l'a fait remarquer le Comité dans son rapport intérimaire, il n'y a pas de choix unique et facile :

**Le langage utilisé pour parler d'un problème, et les modèles employés pour le comprendre, influe beaucoup sur la nature des politiques que l'on favorise ou que l'on avalise par la suite.**

D'habitude, on appelle patients les personnes atteintes de maladie mentale ou de toxicomanie qui sont soignées par des médecins. Les autres professionnels de la santé les appellent souvent clients ou bénéficiaires. Les personnes en cause emploient parfois d'autres termes, comme consommateurs ou réchappés. Les consommateurs sont habituellement les personnes ayant vécu directement d'importants problèmes de santé mentale.

Dans ses premiers rapports, le Comité a choisi d'utiliser l'expression « personnes ayant une maladie mentale » comme référence la plus large. Il a également utilisé le terme « patient/client » lorsque c'était pertinent. Il est important de clarifier davantage l'utilisation de ces divers termes et expressions dans tout le présent rapport.

**En plus des « personnes ayant une maladie mentale » comme expression générique, le Comité emploiera également la phrase « personnes ayant une expérience directe de la maladie mentale ».**

En plus des « personnes ayant une maladie mentale » comme expression générique, le Comité emploiera également la phrase « personnes ayant une expérience directe de la maladie mentale ». D'autres termes seront utilisés le cas échéant. Le terme « patient », par exemple, peut être utilisé lorsqu'on se réfère à des gens qui reçoivent vraiment un traitement médical. Toutefois, utilisé comme terme général, il transmet une impression qui est exagérément médicale; le Comité a maintes fois entendu, et dans des propos convaincants, que le traitement des maladies mentales implique plus que la médecine.

Un participant anonyme à la deuxième consultation électronique du Comité l'a exprimé de cette façon :

*Lorsque le Comité sénatorial formulera ses recommandations finales, j'espère que vous reconnaîtrez que les soins de santé mentale sont plus que des services psychiatriques et cliniques. Même si ces éléments sont extrêmement importants, ils ne peuvent être utiles que dans le cadre d'un système de soutien communautaire plus large qui aborde de façon adéquate les besoins des consommateurs de santé mentale. —Anonyme*

Pour sa part, Jocelyn Green, directrice des Stella Burry Community Services à St. John's, a mis le doigt sur l'incidence potentiellement bénéfique d'une approche plus vaste :

*Le système de santé mentale établi est encore trop hiérarchique et axé sur la pathologie. Oui, il est évident qu'il existe des maladies mentales graves qui nécessitent un traitement et une médication, mais je crois qu'on oublie souvent de prendre en compte les causes systémiques de nombreux problèmes de santé mentale, par exemple la pauvreté, la maltraitance, la discrimination, l'absence de services de garde pour les enfants et l'absence de logements abordables. Je pense que si l'on intervenait dans bon nombre de ces problèmes, il y a beaucoup de monde qui entre dans le système qui n'aurait pas besoin d'être là. — Jocelyn Green<sup>58</sup>*

Le terme « consommateur » présente les mêmes difficultés. Le Comité l'utilisera pour désigner les gens qui utilisent les soutiens et les services de santé mentale disponibles. Toutefois, il ne sera pas utilisé pour désigner toutes les

**Le Comité utilisera le terme « consommateur » pour désigner les gens qui utilisent les soutiens et les services de santé mentale disponibles. Toutefois, il ne sera pas utilisé pour désigner toutes les personnes ayant une maladie mentale.**

personnes ayant une maladie mentale. Une des raisons en est que la majorité des personnes ayant un trouble mental ou une toxicomanie, comme le révèle une enquête nationale effectuée récemment par Statistique Canada<sup>59</sup>, n'ont pas accès à des services ou à des soutiens en santé mentale. Il est clair qu'il est inexact d'appeler *tous* les gens ayant une maladie mentale des « consommateurs »; la même restriction s'applique au terme « client ».

Le Comité est également sensible au fait que le terme « consommateur » a diverses significations et n'est pas aimé de bon nombre des personnes auxquelles il pourrait s'appliquer. Comme l'a écrit un répondant à la consultation électronique du Comité :

*Je n'aime pas le mot « consommateur » — je le trouve stigmatisant. D'autres personnes ayant des maladies ne sont pas définies de cette façon. Cela donne l'impression que nous surutilisons les services à cause de notre maladie. Ce mot me fait penser à un incendie consumant ce qui l'alimente. Il a une connotation très négative et j'estime qu'il faudrait le supprimer. Parler des gens ayant une expérience personnelle de la maladie mentale est tout à fait approprié... tout comme parler des gens ayant une expérience personnelle du cancer ou de toute autre maladie connue. — Anonyme*

D'autres ont souligné les nombreuses nuances commerciales du terme. Pour toutes ces raisons, le Comité est d'avis que ce n'est pas le meilleur terme à utiliser pour désigner le plus largement possible toutes les personnes ayant des maladies mentales. Par conséquent, dans le présent rapport, le Comité utilisera le terme « consommateur » uniquement pour désigner les personnes qui utilisent en fait les soutiens et les services de santé mentale disponibles, ou

<sup>58</sup> 15 juin 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evb-f.htm?Language=f&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evb-f.htm?Language=f&Parl=38&Ses=1&comm_id=47).

<sup>59</sup> Statistique Canada (2003), Enquête sur la santé dans les collectivités canadiennes, Cycle 1.2, Santé mentale et bien-être.

lorsqu'on parle de groupes et de particuliers qui se désignent eux-mêmes comme des consommateurs.

### 3.1.3 Les dimensions mentales et physiques de la maladie

Les personnes ayant une maladie mentale ou une toxicomanie sont et continuent d'être stigmatisés et de subir de nombreuses formes de discrimination qui aggravent les effets de leurs maladies. Comme l'a mentionné précédemment le Comité, cette discrimination systématique explique que la maladie mentale, en général, n'est pas souvent traitée avec autant de sérieux que la maladie physique<sup>60</sup>. Il faut remédier à cette situation.

Le Comité sent qu'il existe, en fait, chez les Canadiens un large consensus en faveur d'un traitement équitable. La plupart de nos concitoyens seraient d'accord pour dire que le fait de voir la maladie mentale traitée avec le même sérieux que la maladie physique par les prestataires et autres intervenants fait partie de l'accès fondamental des gens ayant une maladie mentale aux mêmes droits et privilèges que tous les autres Canadiens. Atteindre un traitement équitable constituerait une étape importante dans la lutte contre le stigmate associé à la maladie mentale ou à la toxicomanie et contre la discrimination envers les gens qui en sont atteints.

Mais il est important de clarifier ce que signifie vraiment «traiter la maladie mentale comme la maladie physique». On est loin d'un accord universel sur la façon dont les facteurs mentaux et physiques influencent l'état de notre santé mentale. De fait, il existe de nombreuses interactions différentes des facteurs sociaux, environnementaux, psychologiques et biologiques dans le développement des troubles mentaux, même si la plupart des gens semblent s'entendre pour dire que les maladies mentales entraînent une certaine combinaison de ces facteurs.

**Les personnes ayant une maladie mentale ou une toxicomanie ont fait et continuent de faire face à un stigmate et à de nombreuses formes de discrimination qui aggravent les effets de leurs maladies.**

Cependant, en mettant différemment l'accent sur le rôle de ces quatre facteurs on peut aboutir, et c'est le cas, à des approches très différentes de la politique sur la santé mentale. Par exemple, une personne qui croit que la clé de la «guérison» de la maladie mentale est une compréhension des fonctions sous-jacentes du cerveau serait plus vraisemblablement encline à dépenser les maigres ressources de recherche sur la neurophysiologie plutôt que sur des études de l'incidence des déterminants sociaux de la santé mentale sur les individus.

De l'avis du Comité, il est primordial de reconnaître qu'en traitant la maladie mentale de façon comparable à la maladie physique, il n'est pas nécessaire de les traiter comme si elles étaient identiques. La maladie mentale et la maladie physique sont à la fois semblables et dissemblables. Il y a des similitudes importantes

**Le Comité est d'avis qu'il est essentiel de souligner l'importance de ce qu'on appelle les déterminants sociaux de la santé dans la compréhension de la maladie mentale et dans la promotion de son rétablissement.**

<sup>60</sup> Voir le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (novembre 2004), Rapport 1— *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 3.

et des différences importantes, de nombreux points de chevauchement, mais également des caractéristiques uniques à chacune d'elles.

En particulier, le Comité est d'avis qu'il est essentiel de souligner l'importance de ce qu'on l'appelle les déterminants sociaux de la santé dans la compréhension de la maladie mentale et dans la promotion de son rétablissement. Les membres du Comité ont entendu à maintes reprises que des facteurs comme le revenu, l'accès à un logement et à un emploi adéquats et la participation à un réseau social de parents et d'amis jouent un rôle bien plus grand dans la promotion de la santé mentale et dans le rétablissement de la santé mentale que dans le cas de la maladie physique. En outre, il est important de constater que la causalité va dans les deux sens, du mental (psychologique, émotionnel, etc.) vers le physique (neurobiologique) et aussi du physique vers le mental.

**Ce que le Comité veut donc dire en parlant de traiter la maladie mentale comme la maladie physique signifie idéalement que les deux types de maladies doivent être traités avec le même sérieux par les prestataires, par tous les Canadiens et les Canadiennes — et en particulier par les gouvernements.**

Ce que le Comité veut donc dire en parlant de traiter la maladie mentale comme la maladie physique signifie idéalement que les deux types de maladies doivent être traités avec le même sérieux par les prestataires, par la population — et en particulier par les gouvernements. Les gens ayant une maladie mentale ou une toxicomanie doivent obtenir un respect et une considération égaux à ceux que l'on accorde aux gens affectés par des maladies physiques. Le Comité a cherché à en faire l'un des principes directeurs qui sous-tendent l'ensemble de ce rapport.

### 3.2 RÉTABLISSEMENT

Le présent rapport insiste sur le fait de faciliter le rétablissement des gens ayant une maladie mentale ou une toxicomanie. Largement documentée dans le domaine des toxicomanies, l'idée du rétablissement n'a été appliquée à la maladie mentale que dans un passé relativement récent (les dix dernières années). L'objectif du rétablissement pour les personnes atteintes d'une maladie mentale a néanmoins bénéficié d'une acceptation considérable au cours de cette période.

**Le Comité est d'avis qu'il faut placer le rétablissement au cœur de la réforme de la santé mentale.**

**Le Comité est conscient que toutes les personnes ayant une maladie mentale ne seront pas capables de se rétablir mais estime que le rétablissement est l'objectif principal autour duquel il faudrait organiser le système de prestation de la santé mentale.**

Le Comité a fait remarquer précédemment que :

*Le rétablissement n'est pas synonyme de guérison. Pour bien des gens, c'est une façon de mener une vie satisfaisante, prometteuse et productive, malgré les limites imposées par la maladie; pour*

d'autres, le rétablissement veut dire la réduction ou la rémission complète des symptômes de la maladie mentale<sup>61</sup>.

Le Comité est d'avis qu'il faut placer le rétablissement au cœur de la réforme de la santé mentale. Des études ont démontré que même les personnes atteintes des maladies mentales les plus graves, qui ont reçu des soins institutionnels pendant des décennies, peuvent se rétablir et y parviennent<sup>62</sup>. Des études à long terme sur l'impact d'une maladie mentale grave ont démontré qu'un nombre important de personnes affectées peuvent récupérer leur fonctionnement total<sup>63</sup>. Des recherches effectuées par le National Empowerment Centre, reposant sur des entrevues approfondies avec des personnes diagnostiquées atteintes de schizophrénie, de troubles bipolaires ou de troubles schizoaffectifs, confirment la capacité de rétablissement<sup>64</sup>.

Même si le terme rétablissement comporte aussi un certain nombre de désavantages, le Comité estime néanmoins que c'est le plus approprié pour toutes les raisons énoncées dans la présente section. Le Comité est conscient que toutes les personnes ayant une maladie mentale ne seront pas capables de se rétablir mais, comme on l'explique ci-après, il estime que le rétablissement est l'objectif principal autour duquel il faudrait organiser le système de prestation de la santé mentale<sup>65</sup>.

Les groupes de défense ont été les premiers à demander que l'on mette l'accent sur le rétablissement. À cet égard, un participant aux consultations électroniques du Comité a fait le commentaire suivant :

*Chose surprenante, si l'on fait l'histoire du traitement psychiatrique, le rétablissement peut être considéré comme un concept radical. La volonté*

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<sup>61</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 4, p. 87.

<sup>62</sup> C. Harding, (1987), « The Vermont Longitudinal Study of Persons With Severe Mental Illness », II. *American Journal of Psychiatry*, vol. 144, pp. 727-735.

<sup>63</sup> M. Moran, (2004), « Schizophrenia Treatment Should Focus on Recovery, Not Just Symptoms », *Psychiatric News* (American Psychiatric Association), vol. 39, n° 22. Également N. Jacobson et L. Curtis, (2000), « Recovery as Policy in Mental Health Services: Strategies emerging from the States », *Psychiatric Rehabilitation Journal*, vol. 23, n° 4.

<sup>64</sup> D. Fisher et L. Ahern, (1999), « People can recover from mental illness », National Empowerment Centre, [http://www.power2u.org/recovery/people\\_can.html](http://www.power2u.org/recovery/people_can.html). Il est intéressant de noter dans ce contexte les résultats d'études effectuées par l'Organisation mondiale de la santé en 1979 et en 1992 qui ont comparé les taux de rétablissement des schizophrènes dans des pays en développement et dans des pays industrialisés. À l'aide de contrôles appariés, ils ont constaté que les taux de rétablissement dans les pays en développement étaient deux fois supérieurs à ceux des nations industrialisées. Certains commentateurs ont émis l'hypothèse que l'approche plus sociale des pays en développement qui cherchait à maintenir les gens en contact avec leurs collectivités contribuait à leur rétablissement.

<sup>65</sup> Le Comité reconnaît qu'il y a un vaste débat entourant l'applicabilité du terme « rétablissement » à certains troubles, en particulier l'autisme. Un certain nombre d'ardents défenseurs des autistes lui ont expliqué que le rétablissement n'est pas leur objectif, parce qu'ils ne considèrent pas l'autisme comme une maladie dont il est nécessaire de se rétablir (voir le Chapitre 6 portant sur les enfants et les jeunes pour d'autres aspects de la question). Ce n'est pas une question que le Comité peut trancher. Il utilisera donc le terme rétablissement comme il est dit dans le présent chapitre.

*de voir le potentiel humain des consommateurs et le désir que l'aide aboutisse au rétablissement ont été engendrés par le mouvement des consommateurs et des familles. —Anonyme*

Kim Baldwin, directrice de la santé mentale et des toxicomanies pour la région de St. John's, a également fait remarquer que :

*Le terme « rétablissement » est un terme que l'on utilise dans le domaine des toxicomanies depuis longtemps. On commence à l'utiliser dans le domaine de la santé mentale aussi. On insiste sur le mieux-être, plutôt que sur la maladie<sup>66</sup>.*

De nombreux témoins ont parlé de l'importance de ce changement d'orientation, dont Jean-Pierre Galipeault, propriétaire de The Empowerment Connection à Dartmouth, Nouvelle-Écosse, qui a donné au Comité une idée des conséquences graves de l'adoption d'un cadre de rétablissement :

*Il existe différentes définitions de la guérison. Mon entreprise, The Empowerment Connection, définit ce mot comme suit : « Lorsque le diagnostic psychiatrique ou le traumatisme affectif et psychologique d'une personne n'est plus le centre d'intérêt dans sa vie, mais devient simplement une partie de la personne ». Nous ne devons pas oublier que les gens sont confrontés à un défi de taille : se rétablir des effets de la stigmatisation extérieure et intériorisée, de l'incapacité apprise, de l'institutionnalisation, de la pauvreté, de l'itinérance et des blessures d'une âme brisée<sup>67</sup>.*

L'historique des personnes chez lesquelles une maladie mentale a été diagnostiquée sont extrêmement variées; un large éventail de traitements, de services et de soutiens peuvent contribuer au rétablissement. Pour la plupart des consommateurs de services de santé mentale, c'est leur médecin de famille qui est le premier, et souvent le seul, port d'escale<sup>68</sup>. L'accès à des psychiatres, des psychologues, des infirmières et d'autres professionnels de la santé peut également contribuer de façon inestimable au bien-être des personnes ayant une maladie mentale. Par la même occasion, des témoins ont aussi fait état de la nécessité d'autres types de services et de soutiens, comme l'a fait remarquer Raymond Cheng (consommateur et pair-conseiller) :

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<sup>66</sup> 14 juin 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>67</sup> 9 mai 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>68</sup> D. Macfarlane, (juin 2005), « État actuel des soins de santé mentale axés sur la collaboration », p. 5, rapport rédigé pour l'Initiative canadienne de collaboration en santé mentale, Mississauga, Ontario.  
<http://www.ccmhi.ca>.

*... ce dont les gens ont besoin, c'est d'un endroit sécuritaire et confortable, ouvert aux heures qui leur conviennent, qui répondent à leurs besoins, et d'avoir un sentiment de communauté, de manger ensemble, de se parler, de rire ensemble et de s'entraider*<sup>69</sup>.

Le rétablissement est de plus en plus englobé dans le secteur plus vaste de la santé mentale<sup>70</sup>, ainsi que dans les cercles gouvernementaux. Par exemple, comme l'a fait remarquer le Comité dans son examen des politiques et des programmes de santé mentale dans d'autres pays, la promotion du rétablissement comme objectif était au cœur d'un récent rapport national portant sur la santé mentale aux États-Unis<sup>71</sup>. Dans la pratique, l'un des attraits d'une orientation vers le rétablissement est que cela pourrait aider à créer un cadre au sein duquel on pourrait mesurer et évaluer utilement les services<sup>72</sup>.

### 3.2.1 La nécessité d'un système axé sur le rétablissement

Deux modèles de rétablissement ont été élaborés : le modèle de réadaptation psychosociale et le modèle de prise en charge de soi. Le premier est né dans le milieu professionnel, tandis que le second provient largement du mouvement de défense des consommateurs. Même si les deux modèles présentent certaines similitudes, ils possèdent également des différences importantes. Souvent utilisés de façon interchangeable par les planificateurs, selon leur mode d'application, les différences philosophiques entre les modèles peuvent aboutir au développement d'approches différentes dans la prestation des services. Les deux modèles sont décrits plus en détail dans l'annexe au présent chapitre.

**Au sens très large, il laisse sous-entendre que l'objectif de la politique de santé mentale devrait viser à permettre aux gens de mener la vie la plus gratifiante, la plus prometteuse et la plus productive, conforme aux limites causées par leur maladie.**

À partir de ces deux modèles<sup>73</sup>, le Comité a conclu qu'une approche stratégique axée sur le concept de rétablissement doit reconnaître les éléments suivants :

- la voie du rétablissement de chaque personne est unique;
- le rétablissement est un processus, pas une fin en soi;

<sup>69</sup> 17 février 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>70</sup> Forum provincial des présidents de groupes d'étude sur la mise en œuvre de la réforme des services de santé mentale, (décembre 2002), « The Time Is Now: Themes And Recommendations For Mental Health Reform In Ontario ».

[http://www.santé.gov.on.ca/english/providers/pub/mhitf/provincial\\_forum/provincial\\_forum.pdf](http://www.santé.gov.on.ca/english/providers/pub/mhitf/provincial_forum/provincial_forum.pdf).

<sup>71</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (novembre 2004), Rapport 2 — *Santé mentale, maladie mentale et toxicomanie : Politiques et programmes de certains pays en matière de santé mentale*, chapitre 4, p. 71.

<sup>72</sup> Association canadienne pour la santé mentale, division de l'Ontario, (mars 2003), « Recovery Rediscovered ».

<sup>73</sup> Voir l'annexe au présent chapitre. Également N. Jacobson et L. Curtis, (2000), « Recovery as Policy in Mental Health Services: Strategies emerging from the States », *Psychiatric Rehabilitation Journal*, vol. 23, n° 4.

- le rétablissement est un processus actif au cours duquel la personne assume la responsabilité du résultat, le succès dépendant principalement de la collaboration entre les amis désireux d'aider, la famille, la collectivité et les soutiens professionnels.

Le rétablissement parle d'espoir. Comme nous l'avons mentionné précédemment, le rétablissement n'équivaut pas forcément à la guérison. Il peut signifier des choses différentes pour des gens différents. Au sens très large, il laisse sous-entendre que l'objectif de la politique de santé mentale devrait viser à permettre aux gens de mener la vie la plus gratifiante, la plus prometteuse et la plus productive possible compte tenu des limites causées par leur maladie. Pour certaines personnes, le rétablissement équivaudra à la réduction ou à la rémission complète des symptômes de maladie mentale.

Dans le passé, une grande partie de la planification de la santé mentale n'a pas mis suffisamment l'accent sur les résultats obtenus par les gens utilisant les services fournis à l'intérieur du système de santé mentale. Le rétablissement offre un point de mire pour réorienter la conception et la prestation des programmes, des services et des soutiens de santé mentale. Élément important, il nous permet de définir le rôle du système, à savoir permettre aux personnes ayant une maladie mentale de tirer le meilleur parti des limites imposées par leur état.

**Le rétablissement permet de définir le rôle du système, à savoir faciliter la capacité des gens ayant une maladie mentale de se pencher activement sur les limites imposées par leur situation.**

Comme l'a dit au Comité Darrell Burnham, directeur administratif de la Coast Mental Health Foundation :

*Le chemin du rétablissement n'est pas clairement tracé sur une carte. À nos yeux, c'est une approche qui doit être tout à fait centrée sur la personne; chaque personne emprunte son propre chemin pour se réinsérer dans la société. Le système doit favoriser et faciliter cela, plutôt que de mettre en place un programme spécifique qui peut préjuger de ce chemin<sup>74</sup>.*

Travailler à l'élaboration d'un système axé sur le rétablissement est une entreprise complexe. Elle implique une action coordonnée de la part des gouvernements à tous les niveaux; or il y a, à chaque niveau, de multiples ministères, agences ou départements, chacun n'ayant généralement qu'une connaissance minimale des agissements des autres. Elle implique des dizaines de milliers de fournisseurs travaillant à la fois à l'intérieur et à l'extérieur du système officiel de soins de santé mentale, certains rémunérés à l'intérieur du système public et d'autres pas, ainsi que des centaines de milliers de soignants non rémunérés, utilisant toutes les ressources qu'ils peuvent trouver pour aider leurs amis et leurs êtres chers, en offrant bénévolement de leur temps et de leur énergie lorsque cela est possible.

**Un système axé sur le rétablissement doit reposer sur trois piliers : le choix, la collectivité et l'intégration.**

<sup>74</sup> 6 juin 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Il existe toujours le danger que l'idée de rétablissement soit acceptée pour la forme mais ne se traduise pas par une politique ni par des actes<sup>75</sup>. Dans les trois prochaines sections du présent chapitre, on suggère de jeter un pont entre la notion de rétablissement et les propositions spécifiques de réforme contenues dans les autres chapitres du présent rapport. De l'avis du Comité, un système axé sur le rétablissement doit reposer sur trois piliers :

- **le choix** : avoir accès à un large éventail de services et de soutiens financés par l'État qui offrent aux personnes atteintes d'une maladie mentale la possibilité de choisir ceux qui leur seront les plus bénéfiques;
- **la collectivité** : offrir ces services et ces soutiens là où les gens vivent et les adapter à la population locale;
- **l'intégration** : intégrer tous les types de services et de soutiens, quels que soient l'ordre de gouvernement, qu'ils soient publics ou privés et fournis par des professionnels ou non.

### 3.3 LE CHOIX

En général, l'éventail des choix mis à la disposition des consommateurs de services de santé mentale a été extrêmement limité. Le système a manqué à la fois des ressources et de la souplesse nécessaires pour offrir des services personnalisés qui mobilisent les personnes pour leur propre rétablissement, qu'elles recherchent un traitement dans un service de soins actifs pour patients hospitalisés ou qu'elles vivent dans leurs collectivités.

**Ce sont les personnes atteintes d'une maladie mentale elles-mêmes qui devraient être, dans toute la mesure du possible, les arbitres ultimes des services rendus, disponibles dans le système global de santé mentale, et des façons dont ils sont dispensés.**

C'est ainsi que l'explique Darrell Downton, co-président du Comité consultatif sur la santé mentale et les toxicomanies, région sanitaire de Five Hills, en Saskatchewan :

*Le peu de possibilités offertes aux personnes souffrant de maladies mentales et de toxicomanies leur confirme qu'elles ne peuvent recevoir les soins et l'aide qu'elles méritent. Leur guérison est limitée aux choix qui existent<sup>76</sup>.*

Pour ce qui est de favoriser le rétablissement, le choix est à la fois un moyen d'atteindre une fin — un service plus réceptif — et une fin en soi, parce que le fait de pouvoir faire des choix est une manifestation des droits et des responsabilités des adultes, et des citoyens de

<sup>75</sup> Dans le domaine plus vaste des soins de santé, la question de la réforme des soins primaires peut constituer une bonne mise en garde. Depuis plus d'une décennie, chaque rapport d'envergure portant sur le système hospitalier et médical au Canada a souligné la nécessité d'une importante réforme des modes de prestation des soins de santé primaires, mais les progrès ont été très lents sur le terrain.

<sup>76</sup> 2 juin 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

plein droit. La disponibilité et l'exercice du choix peuvent en soi contribuer au processus de rétablissement.

Le Comité est d'avis que ce sont les personnes atteintes d'une maladie mentale elles-mêmes qui devraient être, dans toute la mesure du possible, les arbitres ultimes des services rendus, disponibles dans le système global de santé mentale, et des façons dont ils sont dispensés. Dans ce sens, il est légitime d'encourager une approche axée sur les consommateurs ou le choix des consommateurs.

C'est la meilleure façon à la fois d'encourager l'élaboration et la mise en œuvre de solutions pratiques aux problèmes rencontrés par les personnes atteintes d'une maladie mentale ou d'une toxicomanie et de promouvoir le bien-être mental de l'ensemble de la population. Aucun organisme individuel, et encore moins gouvernemental, ne devrait avoir l'arrogance de croire qu'il peut prescrire un modèle de traitement universel pour toutes les personnes atteintes de maladies mentales ou de toxicomanies.

**Les ententes actuelles de financement signifient donc que de nombreux services requis par des personnes atteintes d'une maladie mentale ou d'une toxicomanie ne sont qu'à la disposition de celles qui peuvent payer personnellement pour les obtenir ou qui ont des régimes d'assurance privés qui les couvrent.**

En outre, aucun modèle unique de traitement ne devrait être autorisé à dominer, que ce soit sur le plan théorique ou pratique. Beaucoup trouveront des traitements ou des soins efficaces dans le cadre d'un modèle purement «médical», tandis que d'autres se tourneront vers leur collectivité particulière ou leurs traditions culturelles pour trouver des moyens d'atteindre la meilleure santé mentale possible.

En outre, à cause de la complexité des maladies mentales et de leur lien intime avec les circonstances et l'environnement uniques de chaque individu, bon nombre de gens constateront qu'ils devront s'appuyer sur des traitements, des soutiens et des façons de soigner qui combinent des éléments tirés d'approches multiples.

Accorder aux gens un éventail de choix qui peuvent reposer sur une variété de traditions n'est pas simplement l'expression d'une préférence philosophique — cela a d'importantes répercussions au niveau de la politique nationale. Il faut donc tenir compte du fait qu'un préjugé institutionnalisé est ancré dans le mode de financement des services de soins de santé au Canada : en vertu de la *Loi canadienne sur la santé*, seuls les services fournis par des médecins ou dans des hôpitaux *doivent* être financés par les deniers publics<sup>77</sup>.

Alors que d'autres services peuvent être financés par des provinces ou même au niveau local, leur accès variera considérablement. Les ententes actuelles de financement signifient donc que de nombreux services nécessaires à des personnes atteintes d'une maladie mentale ou d'une toxicomanie ne sont qu'à la disposition de celles qui peuvent les payer de leur poche ou qui ont des régimes d'assurance privés qui les couvrent.

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<sup>77</sup> Voir le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (octobre 2002), *La santé des Canadiens — Le rôle du gouvernement fédéral*, volume six : *Recommandations en vue d'une réforme*, chapitre 17. Veuillez noter que les hôpitaux psychiatriques spécialisés ont été explicitement exclus de la portée de la *Loi canadienne sur la santé* parce qu'ils sont jugés être des établissements de soins de longue durée que la *Loi* n'avait pas l'intention de réglementer.

Les services fournis par les psychologues sont un exemple que le Comité a entendu à maintes reprises. Comme l'a déclaré un répondant à la consultation électronique :

*Le modèle biomédical n'aborde pas les problèmes sous-jacents comme la maltraitance. Je pense que l'origine de ma maladie découle d'actes incestueux commis pendant mon enfance. Les sévices sexuels durant l'enfance ont des conséquences dévastatrices dans la vie d'une personne. Un pourcentage élevé de personnes diagnostiquées avec un trouble de la personnalité limite ont subi des sévices sexuels. Je ne peux pas me permettre de payer un psychologue à 150 \$ de l'heure pour me traiter. La chose la plus importante dont j'ai besoin, c'est d'une thérapie*  
—Anonyme

Un autre répondant a abondé dans le même sens :

*Depuis la «révolution» du traitement pharmacologique des troubles psychiatriques, les psychiatres ont abandonné graduellement le rôle de psychothérapeutes. La psychothérapie n'est couverte par mon régime provincial d'assurance-santé que si elle est fournie par un psychiatre (à titre de médecin). J'ai pris beaucoup plus de médicaments que j'aurais voulu à un coût exorbitant pour ma santé et pour mon régime provincial d'assurance-santé, alors j'aurais pu en prendre beaucoup moins et avoir un rétablissement beaucoup plus rapide si j'avais pu me permettre de la psychothérapie. Si le régime provincial avait payé pour ma psychothérapie, je crois qu'il aurait économisé de l'argent et que ma santé mentale et physique globale en serait devenue meilleure.* —Anonyme

Fournir aux gens atteints d'une maladie mentale l'accès à un éventail complet de services et de soutiens, en plus de ceux fournis par les médecins et les hôpitaux, et leur permettre de choisir librement ceux qu'ils préfèrent exige de mettre à leur disposition une gamme adéquate de services et que les gens aient les moyens de les payer.

Le Comité est conscient qu'il ne sera pas facile de créer les conditions propices à un environnement permettant aux personnes atteintes d'une maladie mentale de choisir les services qui leur sont les plus bénéfiques. Il y aura toujours des décisions difficiles à prendre en matière de politique au sujet de la meilleure utilisation possible des ressources publiques. En outre, personne ne peut escompter que toutes les options seront toujours disponibles gratuitement pour quiconque les souhaite.

**Les consommateurs de soutiens et de services de santé mentale doivent être entendus à la table de formulation des politiques, tout comme ils devraient être autorisés à faire des choix individuels à propos des services et des soutiens qui leur conviennent.**

D'une part, cela signifie que les décisions de politique concernant les services et les soutiens qui devraient être largement disponibles et accessibles aux personnes qui les choisiraient doivent être prises en fonction des meilleures preuves disponibles quant à leur efficacité. Étant donné les dimensions multiples que revêtent les questions de santé mentale (sociales,

environnementales, médicales, biologiques), il faut appliquer un pluralisme méthodologique à la sélection et à l'évaluation de la preuve de l'efficacité elle-même. Pour pondérer une telle preuve, il faut tenir compte à la fois des conclusions pertinentes dérivées des sciences médicales, des sciences sociales et des personnes ayant acquis une expérience directe de la maladie mentale.

D'autre part, la nécessité de fixer collectivement les priorités concernant les dépenses publiques révèle une autre dimension de la promotion du choix. Les consommateurs de soutiens et de services de santé mentale doivent pouvoir participer activement au processus collectif de prise des décisions. Il faut que leur voix collective soit entendue lors de la formulation des politiques, tout comme ils devraient être autorisés à faire des choix individuels à propos des services et des soutiens qui leur conviennent.

### 3.4 LA COLLECTIVITÉ

Une orientation visant à fournir un accès à des soutiens et des services communautaires est le deuxième pilier nécessaire pour appuyer la création d'un système axé sur le rétablissement. Les preuves sont claires que le virage amorcé il y a des années en vue de s'éloigner des modèles institutionnalisés de soins était constructif, même si les ressources qui lui ont été affectées n'ont pas toujours été suffisantes dans la pratique.

De nombreux témoins ont souligné l'importance de cette orientation reposant sur des services communautaires :

**Une orientation visant à fournir un accès à des soutiens et des services communautaires est le deuxième pilier nécessaire pour appuyer la création d'un système axé sur le rétablissement.**

**Pour les personnes souffrant d'une maladie mentale grave, il existe des preuves probantes qu'elles peuvent non seulement vivre dans la collectivité mais également mener une vie enrichissante et productive si les soutiens appropriés sont en place.**

*Dans tous les ouvrages spécialisés que j'ai lus au sujet du rétablissement, toutes les personnes qui se dévoilent à ce sujet précisent que les liens avec un groupe d'abstinents sont cruciaux à la réadaptation en cours. Sinon, ces personnes risquent inévitablement de faire une rechute et de se retrouver de nouveau dans un état qui les empêche de bien fonctionner. —Patricia Commins<sup>78</sup>*

D'autres ont souligné la gamme de ressources nécessaires dans la collectivité pour soutenir et maintenir le processus de rétablissement. Geoff Chaulk, directeur exécutif de l'Association canadienne pour la santé mentale, division de Terre-Neuve et du Labrador, a déclaré au Comité :

*Les modèles fondés sur les ressources communautaires qui sont axés sur les besoins du patient comportent les éléments essentiels à l'intégration*

<sup>78</sup> 15 février 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*communautaire et au rétablissement de la santé mentale, dont un logement et un revenu adéquats, du travail, des rapports sociaux et des services et des mécanismes de soutien dans le domaine de la santé mentale*<sup>79</sup>.

Puisque les problèmes de santé mentale et de toxicomanie recoupent tant de facettes de la vie communautaire, il faudra bien davantage que des soins de santé et d'autres services sociaux financés par l'État pour y répondre convenablement. Le large éventail d'actions communautaires est très utile aux personnes atteintes de maladie mentale ou de toxicomanie; sans lui, les services financés par le Trésor public se retrouveraient face à un défi écrasant. En outre, en faisant de la collectivité le centre de la prestation des services, les gens peuvent demeurer proches de leurs réseaux personnels de soutien.

Mais le D<sup>r</sup> Paul Garfinkel, directeur général du Centre de toxicomanie et de santé mentale, a fait la mise en garde suivante :

*... les soins de santé communautaires sont coûteux et exigent des ressources spécialisées ainsi qu'un personnel qualifié capable de dispenser les soins et le traitement. Nous avons un programme de traitement des troubles psychotiques qui nous permet de procurer des soins à une centaine de personnes affligées de schizophrénie. Notre équipe fait des visites à domicile à Toronto, ce qui permet à ces gens de rester chez eux sans problème. C'est un programme de traitement excellent qui compte une centaine de patients qui, autrement, auraient été hospitalisés. Mais c'est un programme coûteux. Il faut un médecin, une infirmière, un travailleur social, toute une équipe.*<sup>80</sup>

L'importance d'un ancrage des soutiens et des services de santé mentale dans la collectivité vaut pour toutes les personnes atteintes de toutes les sortes de maladies mentales, depuis les plus légères jusqu'aux plus graves. Mais les mécanismes assurant la meilleure prestation des soutiens et des services nécessaires varieront selon la gravité de la maladie ainsi que les capacités individuelles à s'adapter aux limites découlant des maladies.

Pour les personnes souffrant d'une maladie mentale grave, il existe des preuves probantes qu'elles peuvent non seulement vivre dans la collectivité mais également mener une vie enrichissante et productive si les soutiens appropriés sont en place.

Un rapport publié récemment par la Community Mental Health Evaluation Initiative in Ontario a conclu, par exemple, que des programmes comme la gestion intensive des cas ou le suivi intensif dans le milieu, qui sont conçus pour aider les personnes atteintes d'une

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<sup>79</sup> 15 juin 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>80</sup> 17 février 2005,

[http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

maladie mentale grave à rester dans la collectivité, « aidaient les clients à réduire leur dépendance vis-à-vis des soins institutionnels et à améliorer leur qualité de vie »<sup>81</sup>.

Le même rapport faisait mention de données tirées d'une étude effectuée à Ottawa qui révèle que :

... en moyenne, fournir des services communautaires à une personne atteinte d'une maladie mentale coûte environ 68 \$ par jour. Toutefois, traiter la même personne à l'hôpital coûterait 481 \$ par jour<sup>82</sup>.

Évidemment, les services hospitaliers constitueront toujours un volet essentiel de l'éventail de soins. Néanmoins, une autre étude, en provenance de la région des Cantons de l'Est au Québec, a révélé qu'en fournissant des installations communautaires appropriées, il était possible pour une région de près de 300 000 personnes de répondre aux besoins à long terme des personnes atteintes d'une maladie mentale grave dans une région qui n'a jamais eu d'établissement psychiatrique spécialisé.<sup>83</sup>

Une préférence pour les traitements dans la collectivité aura une signification différente pour les personnes atteintes de troubles de santé mentale légers à modérés. Pour la plupart d'entre elles, le contact avec le système de santé mentale se fera par le biais d'un dispensateur de soins primaires (en groupe ou individuellement), qui pourra ou non les mettre par la suite en relation avec un service quelconque de santé mentale spécialisé.

Des données épidémiologiques révèlent que, chaque année, près de 3 p. cent des citoyens connaîtront une grave maladie mentale et qu'environ 17 p. cent d'autres seront atteints d'une maladie légère à modérée. Il faut donc que tout l'éventail des services soit disponible pour répondre aux besoins des deux grandes catégories de personne. La Figure 1 [voir p. 21] fournit une représentation graphique d'un système qui place les individus dans son centre ainsi que des types de traitements, de soutiens et de services qui doivent être en place pour répondre aux besoins de toutes les personnes atteintes de troubles mentaux.

L'équilibre le plus approprié entre les divers éléments variera d'une collectivité à l'autre et évoluera vraisemblablement à mesure qu'on en saura davantage sur les genres d'intervention qui facilitent vraiment le rétablissement chez les personnes atteintes de toute la gamme des maladies mentales. Cependant, le point de départ pour réfléchir sur la façon d'améliorer le système de santé mentale devrait être les principaux genres de traitements, de soutiens et de services de santé mentale qui sont dispensés à l'heure actuelle. C'est ce qu'illustre la Figure 1.

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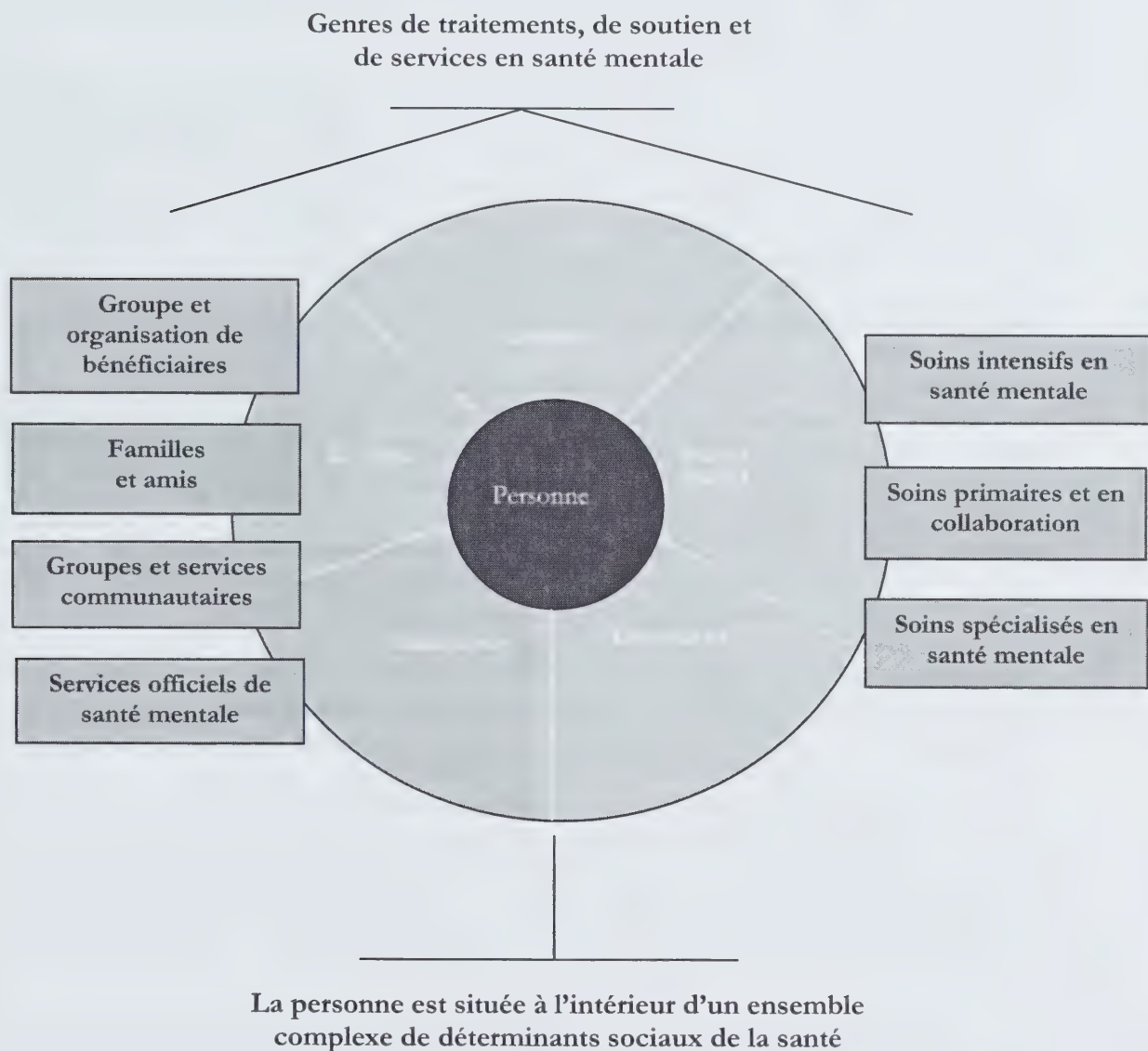
<sup>81</sup> Community Mental Health Evaluation Initiative de l'Ontario, (octobre 2004), « Making a Difference », p. 5 [traduction].

<sup>82</sup> *Ibid.*, p. 9.

<sup>83</sup> Trudel, J.-F. et Lesage, A. (2005) Le sort des patients souffrant de troubles mentaux très graves et persistants lorsqu'il n'y a pas d'hôpital psychiatrique : étude de cas. *Santé mentale au Québec*, Vol. XXX, N° 1, pp. 47-71.

**Figure 1**

Source: Adaptation du document du ministère de la Santé et du Mieux-être du Nouveau-Brunswick intitulé, *Centres de santé mentale communautaires : Programmes et services*, p. 3, trouvé à l'adresse : <http://www.gnb.ca/0055/cmhcs-f.asp>



### 3.5 INTÉGRATION

La séparation entre les services et les soutiens qui sont dispensés par le biais du système de soins de santé et ceux qui relèvent largement d'autres sphères de responsabilité, comme l'illustre la Figure 1, montre bien que de nombreux obstacles institutionnels et structurels entravent une prestation « continue » des soutiens et des services de santé mentale.

**De nombreux obstacles institutionnels et structurels entravent une prestation «continue» des soutiens et des services de santé mentale.**

D'une part, au sein même du secteur de la santé, les services de santé mentale doivent être intégrés avec les services de soins de santé physique. Il faut trouver des façons d'améliorer le diagnostic et le traitement de nombreuses maladies au niveau des soins primaires, ainsi que des façons d'intégrer de meilleurs soins spécialisés aux services de soins primaires.

**La diversité des traitements et des services de santé mentale financés par les ministères de la Santé doit également être intégrée à l'éventail plus large des services, requis par les gens atteints d'une maladie mentale.**

D'autre part, la panoplie de traitements et de services de santé mentale financés par les ministères de la Santé doit également être intégrée à l'éventail plus large des services, nécessaires aux personnes atteintes d'une maladie mentale, qui incombent aux divers ministères et organismes gouvernementaux responsables du soutien du revenu, du logement, de l'emploi, etc. En outre, il est essentiel que les services et les soutiens aux personnes atteintes à la fois de maladie mentale ou de toxicomanie soient mieux intégrés.

**L'intégration exige également que les services et les soutiens soient mis à la disposition des gens durant toute leur vie.**

Enfin, l'intégration exige également que les services et les soutiens soient mis à la disposition des intéressés durant toute leur vie et que, à mesure que leurs besoins changent par suite du vieillissement ou des circonstances, ils soient encore accessibles de manière « continue ».

Il faut relever de nombreux défis pour intégrer les services et les soutiens, ce qui, selon de nombreux témoins, est indispensable pour améliorer l'accès aux services requis et pour ériger un système qui encourage le rétablissement. En premier lieu, il faut reconnaître que l'intégration peut se dérouler de nombreuses façons et qu'il est donc important d'adapter les stratégies pour réaliser l'intégration selon des modalités appropriées à la situation particulière de chaque collectivité.

À cet égard, un rapport préparé par des chercheurs au Centre de toxicomanie et de santé mentale, intitulé *Strategies for Mental Health Integration*, souligne les nombreuses dimensions du problème d'intégration des services de santé mentale. Il cite des recherches insistant sur la nécessité de faire la distinction entre trois domaines — la gouvernance, l'administration et la prestation des services.

La gouvernance désigne la partie du système ayant la responsabilité du rendement du système et l'autorité pour établir l'orientation stratégique et la politique et pour surveiller la gestion générale et l'utilisation des ressources. L'administration est le domaine qui soutient

les opérations sur une base quotidienne et englobe l'infrastructure pour les finances, l'information, les ressources humaines, etc. Le service est la partie de l'organisme qui fournit des services et des soutiens directement aux consommateurs.

Le rapport fait remarquer que l'intensité de l'intégration peut varier (depuis des alliances souples jusqu'à des organisations fortement intégrées), tout comme le caractère officiel (allant d'ententes informelles ou verbales à des politiques, règles et modalités officielles)<sup>84</sup>. Les preuves résumées dans le rapport laissent entendre qu'il est difficile de tirer des conclusions définitives à propos de la façon idéale de réaliser l'intégration ou l'érection du système. Il ne semble pas que la meilleure façon de réaliser l'intégration soit d'en faire une mesure d'économie, ou que toutes les approches de l'intégration du système donnent le résultat escompté.

Néanmoins, on a dégagé un certain nombre d'avantages qui peuvent découler d'une plus grande intégration des services de santé mentale, en faisant remarquer que plusieurs études ont démontré les répercussions positives d'initiatives par le biais desquelles :<sup>85</sup>

- un gestionnaire du système contrôle une enveloppe de financement commune;
- des objectifs de rendement sont fixés et surveillés;
- l'organisation des services dans le réseau est centralisée autour d'un organisme principal (mais pas forcément collectif);
- le gestionnaire du système exerce un contrôle sur les services offerts aux patients hospitalisés et surveillent les entrées.

D'autres ont également fait des commentaires sur les défis fondamentaux que pose le changement des structures de gouvernance dans le secteur plus large des soins de santé. Par exemple, Mintzberg et Glouberman ont fait remarquer que :

Les activités cliniques ne peuvent pas être coordonnées par les interventions des gestionnaires — pas par des patrons ou des coordonnateurs de l'extérieur, pas par des systèmes administratifs, pas par des discussions sur la «qualité» déconnectées du mode de prestation, non pas par toute cette réorganisation constante... *La gestion des opérations cliniques devra être effectuée par les personnes gérées, pas par les gestionnaires.*<sup>86</sup>

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<sup>84</sup> Centre de toxicomanie et de santé mentale, (2001), « Strategies for Mental Health Integration: A Review », p. 13.

<sup>85</sup> *Ibid.*

<sup>86</sup> Glouberman, S. et Mintzberg, H. (Hiver 2001) Managing the Care of Health and the Cure of Disease, Parties I et II. Dans Health Care Management Review, Vol. 26, numéro 1, pp. 72-4 (soulignement ajouté). Everett, B., Lurie, S. et Higgins, C. (2001). The Whole Picture: A provincial framework for redesigning the Ontario mental health system. Association canadienne pour la santé mentale, division de l'Ontario, et Fédération des programmes communautaires de santé mentale et de traitement des toxicomanies de l'Ontario.

En mars 2000, la Commission de restructuration des services de santé (CRSS) de l'Ontario, sous la présidence de Duncan Sinclair, a publié un rapport permettant de réfléchir sur son mandat et sur les tentatives de restructuration du système hospitalier en Ontario. La CRSS a fait les observations suivantes à propos du changement organisationnel et de la gouvernance :

- «Il n'y a pas un système ou un modèle de régie «optimal», mais il faut trouver de meilleures façons pour promouvoir une plus grande intégration et une plus grande efficacité parmi les diverses composantes du système de santé. »
- De nouveaux modèles de régie doivent émerger qui permettront aux organisations individuelles de démontrer les forces et leurs talents à déléguer leurs responsabilités collectives et à préserver et améliorer chaque organisation et institution.»<sup>87</sup>

Enfin, dans un document portant sur «la collaboration autorisée», Steve Lurie a examiné les implications, pour la réforme de la santé mentale, du fait «qu'il existe des preuves limitées que la réforme structurelle ou organisationnelle améliore les résultats cliniques».<sup>88</sup> Voici les leçons générales qu'il a tirées à propos des efforts d'intégration du système :

- il n'y a pas de solution uniformisée;
- il faut utiliser les meilleures pratiques et unifier les modèles de financement pour opérer le changement du système;
- il faut prêter attention aux questions de culture d'entreprise et de ressources humaines quand on veut effectuer un changement structurel ou bâtir une alliance;
- Rome ne s'est pas faite en un jour; le développement de relations de collaboration efficaces prend du temps;
- il faut expérimenter, évaluer et apprendre par l'expérience.

Il est possible d'identifier de nombreux moyens potentiels d'améliorer l'intégration des soutiens et des services de santé mentale. En voici une liste partielle :

- accroître l'utilisation d'équipes multidisciplinaires, de soins partagés et d'ententes de soins en collaboration;
- élaborer des protocoles communs d'évaluation;
- regrouper le financement;

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<sup>87</sup> Commission de restructuration des services de santé de l'Ontario. (2000) Regard sur le passé, regard vers l'avenir : Rapport de travail. Cité dans Everett, Lurie et Higgins (2001).

<sup>88</sup> Lurie, S. (Juin 2002) Mandated Collaboration: Command and Control or Emergent Process. Association canadienne pour la santé mentale, succursale du Toronto métropolitain, p. 37.

- mettre en place des registres des services disponibles;
- établir un lien entre les systèmes de données et les dossiers électroniques de la santé;
- créer des autorités en santé mentale ou s'engager dans la planification régionale;
- élaborer des protocoles de services communs et des chemins d'accès aux soins.

Le Comité estime qu'il est important de permettre aux régions et aux collectivités de poursuivre des formes d'intégration qui conviennent à leurs situations particulières. Chaque collectivité et chaque région devrait choisir des stratégies qui tiennent compte de sa réceptivité au changement et des options disponibles pour améliorer l'accès aux services.

Par exemple, nous décrirons plus tard quelques-uns des moyens qui ont permis d'intégrer avec succès les services de santé mentale à Brandon au Manitoba. Même si l'expérience de Brandon est exemplaire à maints égards, il est bien évident qu'il serait extrêmement difficile de la répéter avec précision dans d'autres collectivités du pays. Non seulement il a fallu 25 ans de dur labeur à un groupe dévoué de personnes de Brandon pour restructurer et coordonner leurs services de santé mentale communautaires, mais leur succès est également bâti sur une histoire très particulière de désinstitutionnalisation qui a fourni un contexte de changement absent dans bien d'autres collectivités. Néanmoins, on peut en apprendre beaucoup de cette expérience.

**Il est important de permettre aux régions et aux collectivités de poursuivre des formes d'intégration qui conviennent à leurs situations particulières.**

**Il est encore capital que l'intégration soit reconnue comme une dimension primordiale de l'érection d'un système de santé mentale axé sur le rétablissement.**

Même si l'approche de l'intégration doit reposer sur l'histoire et les circonstances particulières de chaque collectivité, il est encore capital que l'intégration soit reconnue comme une dimension primordiale de l'érection d'un système de santé mentale axé sur le rétablissement. À certains égards, l'intégration est un ingrédient indispensable pour offrir aux personnes atteintes d'une maladie mentale ou de toxicomanie un système de diffusion vraiment continu capable de satisfaire leurs besoins durant toute leur vie.

Même s'il n'y aura jamais de modèle unique pour accomplir tout cela, l'objectif du rétablissement est d'alimenter les efforts visant à réformer le système de santé mentale. L'intégration doit être considérée comme un moyen d'atteindre cet objectif et non pas comme une fin en soi — elle doit servir l'objectif d'améliorer l'éventail, l'abordabilité, la qualité et l'accessibilité des services, ce qui exige un dosage, une imputabilité et un engagement envers le changement.

### 3.6 TRANSFORMER LA VISION EN RÉALITÉ

Le reste du présent rapport décrira les changements nécessaires si l'on veut réaliser des progrès en vue de créer un système de santé mentale axé sur le rétablissement qui reposera

sur les trois piliers solides que sont le choix, la collectivité et l'intégration. Il y aura de nombreux obstacles concrets à surmonter, dont bon nombre ont été documentés dans les documents d'information du Comité et récapitulés avec éloquence dans les témoignages des témoins et des participants aux consultations électroniques du Comité, qui ont été cités dans les deux premiers chapitres du présent rapport.

Parfois, la tâche peut être écrasante, en partie parce que la réalisation de progrès dans un secteur semble dépendre de la réalisation de progrès dans tous les secteurs. Le Comité pense vraiment qu'en dépit de l'ampleur du défi, il est possible d'avancer mais seulement si on élabore un plan stratégique et si on adopte une approche graduelle pour sa mise en

**Le Comité pense vraiment qu'en dépit de l'ampleur du défi, il est possible d'avancer mais seulement si on élabore un plan stratégique et si on adopte une approche graduelle pour sa mise en œuvre.**

œuvre. Nous reconnaissons qu'il est en fait impossible de transformer d'un seul coup tout le système de prestation de la santé mentale. Cependant, une réforme pragmatique permettant de réaliser de véritables améliorations dans la vie des personnes atteintes de maladie mentale ou de toxicomanie est réalisable et doit se réaliser, et très rapidement.

Le Comité est profondément conscient que le présent rapport ne contiendra pas toutes les réponses aux nombreux défis auxquels sont confrontés des milliers de Canadiens préoccupés par la santé mentale et la toxicomanie. En lui-même, un rapport parlementaire ne peut jamais garantir que des actions suivront ses recommandations. En outre, les efforts déployés pour mettre en œuvre un plan de réforme doivent s'échelonner sur une période de temps considérable.<sup>89</sup>

Néanmoins, durant ses audiences publiques, le Comité a été encouragé par le sentiment que le moment est peut-être idéal pour progresser dans des secteurs clés. En outre, comme on pourra le constater, le Comité a travaillé très fort pour s'assurer de maintenir le vent de changement qui a soufflé de plus en plus fort durant les trois années au cours desquelles nous nous sommes penchés sur ce problème. À cet égard, l'une des recommandations formulées dans le présent rapport (voir le Chapitre 16) ressort comme un élément clé du processus visant à transformer le système de prestation de la santé mentale au Canada.

Le Comité est d'avis qu'il sera possible de garder un point de mire à l'échelle nationale sur les questions de santé mentale et de réunir tous les intervenants qui auront un rôle à jouer dans la transformation du système, uniquement si l'on crée, immédiatement après la publication

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<sup>89</sup> À cet égard, le Comité prend note du fait que, même dans des pays comme l'Australie qui ont établi une norme internationale en matière de planification de la santé mentale, il y a des indices de la difficulté à soutenir l'élan d'une réforme. Dans un rapport récent (mai 2005) adressé à un comité parlementaire et intitulé *Not a Failure of Policy, It Is a Failure of Implementation and Delivery*, la Mental Health Commission of Australia écrit que «les cinq ou six dernières années ont vu une importante initiative de politique perdre son orientation et montrer des signes de stress et même de crise». Elle identifie un certain nombre de causes pour cette évolution, notamment : (a) «le fardeau de la maladie mentale et de l'incapacité connexe au sein de la collectivité n'est pas compensé par le financement alloué pour prévenir, soulager et réadapter les personnes atteintes d'une maladie mentale»; (b) «il y a un décalage important entre le modèle communautaire de services de santé mentale et le système actuel qui affecte encore le financement largement selon l'ancien modèle de services 'des lits et des édifices'»; et (c) «l'incapacité à s'entendre sur un cadre national d'imputabilité et à le mettre en œuvre».

de ce rapport, la Commission canadienne de la santé mentale qui est recommandée au Chapitre 16. À cet égard, la nouvelle Commission canadienne de la santé mentale constitue un mécanisme essentiel pour réaliser la vision énoncée dans le présent chapitre et pour mettre en œuvre les mesures de réforme décrites et recommandées dans le reste du présent rapport.

### 3.7 RÉSUMÉ DES PRINCIPES

Les principes énoncés dans le présent chapitre peuvent se résumer comme suit.

1. Même si la maladie mentale et la maladie physique sont à la fois semblables et dissemblables, elles doivent être traitées avec le **même** sérieux et il faut accorder aux personnes atteintes de maladies mentales et physiques le **même** respect et la **même** considération.
2. L'objectif central de la politique de la santé mentale vise à créer le meilleur contexte possible pour encourager le **rétablissement**; en insistant sur le rétablissement, on met l'accent sur le mieux-être et non sur la maladie et on se fixe comme objectif d'aider les personnes atteintes de maladie mentale à affronter activement les limites imposées par leur situation et à mener une vie utile et productive.
3. Promouvoir la santé mentale et le rétablissement de la maladie mentale **exige** des interventions qui se penchent sur les **déterminants sociaux de la santé** — en particulier ceux qui se rapportent au revenu, à un logement et à un emploi adéquats et à une participation aux réseaux sociaux.
4. Une démarche reposant sur l'idée du rétablissement doit reconnaître que :
  - la voie du rétablissement est unique pour chaque personne;
  - le rétablissement est un processus, pas une fin en soi;
  - le rétablissement est un processus actif durant lequel la personne assume la responsabilité de son propre rétablissement et le succès dépend de la collaboration entre les amis disposés à aider, les parents, la collectivité et les soutiens professionnels.
5. Mettre l'accent sur le rétablissement exigera de réorienter la conception et la prestation des programmes de santé mentale; un système axé sur le rétablissement doit reposer sur trois piliers :
  - **le choix** : l'accès à un large éventail de soutiens et de services financés par l'État qui offrent aux personnes atteintes de maladie mentale la possibilité de choisir ceux qui leur seront les plus bénéfiques;
  - **la collectivité** : rendre ces services et ces soutiens disponibles dans les collectivités où les gens vivent et les orienter vers l'appui aux personnes qui vivent dans la collectivité;

- **P'intégration** : l'intégration de tous les genres de services et de soutiens à tous les ordres de gouvernement et au-delà des séparations public/privé et professionnels/non professionnels.
6. Les décisions stratégiques, d'après lesquelles les traitements, les services et les soutiens devraient obtenir des fonds publics, doivent reposer sur les meilleures preuves disponibles, notamment les découvertes médicales, les données et les analyses des sciences sociales et les témoignages de personnes ayant une expérience directe de maladie mentale

## ANNEXE: MODÈLE DE RÉTABLISSEMENT

### 1) Le modèle de réadaptation psychosociale

Le modèle de réadaptation le plus largement utilisé est le Modèle de réadaptation psychosociale (RPS) provenant de l'Université de Boston.

La RPS est un modèle professionnel qui a façonné l'élaboration de nombreux programmes et services communautaires.<sup>90</sup> Il repose sur l'idée que les personnes atteintes de maladie mentale peuvent se rétablir même si leur maladie n'est pas guérie. La RPS insiste sur l'amélioration de la capacité fonctionnelle et s'efforce d'examiner tous les éléments de la vie d'une personne, incluant les points forts, les ressources et les obstacles. L'approche de la RPS cherche à améliorer quatre domaines de la vie :

- les habiletés pratiques des autosoins,
- la gestion du foyer,
- les relations et l'utilisation des ressources communautaires,
- les loisirs, l'éducation et l'emploi.

L'objectif est d'aider les gens à récupérer un fonctionnement social malgré leurs symptômes, leurs limites et leurs médicaments. Le spécialiste en RPS aide la personne à essayer d'atteindre des buts de la vie autosélectionnés et utiles et fournit les soutiens sociaux et thérapeutiques appropriés pour l'aider à y parvenir. On enseigne des habiletés spécifiques aux objectifs pour encourager l'autonomie, en s'appuyant sur les systèmes de soutien naturels sociaux et communautaires.

Dans le cadre de ce modèle, la maladie mentale est considérée comme une déficience permanente, de la même façon qu'une lésion médullaire engendre une paralysie permanente. On considère que les gens ont «le cerveau en panne» et qu'ils peuvent continuer à fonctionner dans la société avec des soutiens appropriés et adéquats. Cependant, leur déficience demeure permanente.<sup>91</sup>

Les principes fondamentaux qui étayent la RPS peuvent être énoncés comme suit. La RPS :

1. insiste sur la nécessité d'avoir des interventions individuelles sur mesure;
2. exige que les capacités de la personne soient adaptées aux réalités environnementales ou que l'environnement soit modifié pour correspondre aux capacités de la personne;
3. s'appuie sur les points forts de la personne;

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<sup>90</sup> Jacobson, N. et Curtis, L. (2000) Recovery as Policy in Mental Health Services: Strategies emerging from the States. *Psychiatric Rehabilitation Journal*, Vol. 23, N° 4.

<sup>91</sup> *Ibid.*

4. vise à rétablir l'espoir;
5. souligne le potentiel professionnel de la personne;
6. dépasse les activités professionnelles pour englober toute une gamme d'activités sociales et récréatives;
7. implique activement les personnes dans leurs soins personnels;
8. est un processus permanent qui doit se poursuivre au fil du temps.

La réadaptation psychosociale met l'accent sur une intervention précoce, le mieux-être, l'indépendance, l'autodétermination et, élément très important, l'espoir. On se sert de la thérapie cognitive, ou du processus d'apprentissage d'un langage autopersuasif positif et autoaméliorant, pour aider les gens à mieux comprendre et à gérer les symptômes pénibles de la maladie. On constate que le soutien mutuel, grâce aux groupes d'entraide par les pairs, améliore l'autosuffisance et élargit les réseaux sociaux, bâtit l'autonomie de chaque personne et surmonte la dépendance à l'égard des professionnels.

La foi dans la capacité personnelle de croissance du client, l'établissement de partenariats utiles et de services continus s'appuyant sur les préférences et les besoins individuels sont les éléments fondamentaux du modèle psychosocial. Les clients reçoivent une évaluation permanente pour garantir des progrès continus.

Les stratégies englobent l'éducation face à la maladie, l'intervention de la famille, l'emploi assisté, le suivi intensif dans le milieu (TCA), le perfectionnement des compétences et la thérapie cognitivo-comportementale.

La pratique de la réadaptation psychosociale est effectuée par des professionnels en exercice comme les psychiatres, les psychologues, les travailleurs sociaux, les ergothérapeutes et les infirmières, ayant tous les compétences et la formation nécessaires, ou par des personnes ayant reçu une formation spécifique en réadaptation psychosociale dans le cadre de programmes universitaires.

L'approche «axée sur la clientèle» utilisée par les spécialistes de la RPS a été parfois critiquée car elle «colonise» la vie des consommateurs parce que les professionnels sont engagés activement non seulement pendant les périodes de maladie mais également lorsque les gens sont en bonne santé. Il y a eu des cas où des professionnels ont réclamé la propriété et la responsabilité non seulement de la gestion de la maladie mais également des rôles social, récréatif et professionnel. Cela a déclenché la réaction de certains consommateurs qui ont déclaré que *«Lorsque vous dites 'axé sur la clientèle', je me sens encadré»*.<sup>92</sup>

Le Dr William Anthony, «fondateur» du mouvement de réadaptation psychosociale, insiste sur le fait que le rétablissement peut se dérouler sans intervention professionnelle. La tâche des professionnels consiste à faciliter ce processus naturel.<sup>93</sup> Il a nommé les années 90 la «décennie du rétablissement» à cause des gains obtenus pour aider les gens à s'adapter à la vie communautaire. Cependant, il avertit que les années 2000 doivent être «la décennie de la personne».

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<sup>92</sup> Initiative canadienne de collaboration en santé mentale. (2004) Consultations auprès des consommateurs de l'Ontario.

<sup>93</sup> Anthony, W. A. (1993) Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, Vol. 16, pp. 11-23.

À son avis, la réadaptation doit être effectuée «avec» les clients et pas «pour» eux. Il estime que les gens peuvent faire des choix utiles et reconnaît qu'un hommage respectueux a été rendu au concept de l'autodétermination. Le fait de croire que les personnes atteintes de maladie mentale fixent des objectifs irréalistes et ne peuvent pas occuper des emplois exigeants a fait en sorte que des professionnels ont retiré des choix à des consommateurs «pour leur propre bien». Autrement dit, «si on permet aux gens de choisir, ils pourraient demander quelque chose qui exige de changer nos actions ou nos programmes».<sup>94</sup>

## 2) Modèle de prise en charge de soi

Le milieu de la défense des consommateurs s'est fait le champion du modèle de prise en charge de soi comme moyen de promouvoir l'idée que les patients psychiatriques sont capables de travailler et de mener une vie indépendante et ne devraient pas être définis en fonction de leur «diagnostic». Les partisans du modèle de prise en charge de soi prétendent que la désignation de la maladie mentale comme un état permanent est l'un des facteurs qui contribuent à ostraciser les personnes atteintes de maladie mentale vis-à-vis de la société.<sup>95</sup>

Pour les défenseurs des droits des « consommateurs », le rétablissement a des implications politiques aussi bien que personnelles — c'est une philosophie dotée d'un ensemble de valeurs et de principes organisationnels qui peuvent orienter le développement de soutiens et de services ainsi que leur mode d'organisation et de prestation.

À cette condition, se rétablir consiste à récupérer sa vie, à obtenir une validation comme personne autonome et compétente. C'est souligner le fait que l'on est responsable de sa vie et que l'on jouit de la liberté de choix, ce qui comprend le droit de commettre des erreurs. En outre, c'est insister sur le fait que les professionnels ne peuvent pas façonner l'esprit du rétablissement.

Comme l'a mentionné au Comité un répondant aux consultations électroniques :

*Le changement systémique ne viendra pas des professionnels qui expérimentent ces maladies à travers le prisme des universitaires, mais de l'expérience vécue par les consommateurs et les familles. Demandez à un professionnel ce qu'il faut et il vous répondra toujours davantage de services professionnels. Demandez à un consommateur et à un membre de sa famille et ils vous diront qu'ils souhaitent et espèrent un rétablissement. Faire partie de la collectivité, être un membre utile et apprécié de la société avec des amis et un foyer sécuritaire. Nul médicament ne contribuera à atteindre ces objectifs. Même si, pour bien des gens, les médicaments constituent un élément très important pour dégager la voie conduisant au mieux-être. —Anonyme*

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<sup>94</sup> Anthony, W. A. (2003) The Decade of the Person and the Walls that Divide Us. Behavioural Healthcare Tomorrow. <http://www.bu.edu/cpr/catalog/articles/2003/anthony2003c.pdf>.

<sup>95</sup> Fisher, D. B. (1999) A New Vision of Recovery: People can fully recover from mental illness; it is not a life-long process. National Empowerment Centre. [http://www.power2u.org/rétablissement/new\\_vision.html](http://www.power2u.org/rétablissement/new_vision.html).

Le rétablissement est compris comme une manifestation de la prise en charge de soi. Dans ce cadre, le rétablissement survient lorsqu'il y a un mélange de mécanismes de soutien pour rétablir la fonction sociale et des compétences suffisantes en matière d'autogestion pour prendre le contrôle des principales décisions affectant notre vie.<sup>96</sup>

Selon The Empowerment Connection :

Le rétablissement est l'expérience vécue par des personnes qui découvrent, acceptent et surmontent les défis d'une déficience, les effets d'un diagnostic psychiatrique ou un traumatisme émotionnel ou psychologique. C'est la découverte d'un nouveau sentiment de soi, d'espoir et de but bien précis à l'intérieur et au-delà des limites de ces expériences. C'est la découverte de ses propres forces et d'un sentiment de puissance et de contrôle à l'intérieur de soi et dans le monde. Enfin, le rétablissement surgit lorsque le diagnostic psychiatrique ou le traumatisme émotionnel d'une personne n'est plus au coeur de la vie de cette personne, mais devient simplement une partie de son identité.

Ce n'est pas seulement de la maladie mentale et du traumatisme psychologique que les gens doivent se rétablir; ils ont également pour tâche de se rétablir des effets d'un stigmaté intériorisé, d'une impuissance apprise, d'une institutionnalisation, de la pauvreté, de l'itinérance et des blessures d'un esprit brisé<sup>97</sup>.

Le rétablissement par la prise en charge de soi est une approche axée sur les valeurs qui place les gens en premier et affirme que l'expérience de la maladie n'est pas permanente. Cela signifie que le rétablissement est non seulement possible, mais qu'il est attendu. Le rétablissement est considéré comme un processus interne continu qui installe la personne au centre de son propre rétablissement. Il n'est pas considéré comme un processus linéaire avec un point final ou une destination finale. Cette approche du rétablissement suppose également que les personnes sont des « experts » de leurs propres soins. La reprise des relations sociales est jugée cruciale pour le rétablissement, en particulier avec les pairs qui ont une compréhension viscérale de l'expérience de la maladie mentale<sup>98</sup>.

Le rétablissement par la prise en charge de soi ne suggère pas que les services professionnels ne sont pas importants ni nécessaires. Cependant, de tels services ne sont pas destinés à « remettre en état » la personne, mais plutôt à la soutenir dans son mouvement vers une vie saine. Les personnes atteintes de maladie mentale sont considérées comme les agents du changement et les professionnels constituent une des ressources à consulter. Dans ce modèle, le traitement psychiatrique est considéré comme faisant partie des soins autogérés.

L'adoption d'une telle approche implique de s'éloigner de l'objectif voulant que le traitement stabilise la maladie par la réduction des symptômes. Au lieu de cela, l'objectif consiste à aider

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<sup>96</sup> *Ibid.*

<sup>97</sup> <http://www.empowermentconnection.com/approach.html> [traduction]

<sup>98</sup> « An Empowerment Model of Recovery from Severe Mental Illness: An Expert Interview with Daniel B. Fisher, MD, PhD », (janvier 2005), *Medscape, Psychiatry & Mental Health*, vol. 10, n° 1.

les gens à acquérir une plus grande indépendance et un meilleur contrôle de leur propre vie. La médication est utilisée comme un outil pour aider les gens à atteindre cet objectif — pas comme une solution à leurs problèmes. La consommation permanente de médicaments n'empêche pas le rétablissement. Elle est plutôt considérée comme un supplément utile pour aider les gens à prendre le contrôle lorsqu'ils sont effrayés ou désorientés.

À l'intérieur de ce modèle de rétablissement, on peut avoir accès aux soutiens et aux services sans exiger l'acceptation du processus de diagnostic (étiquetage). Les professionnels contribuent à favoriser le rétablissement en croyant en la capacité de leurs clients de guérir et en reconnaissant leur droit de prendre des décisions, même au risque d'échouer. Exiger le respect et l'observation de l'autorité professionnelle est considéré comme une interférence avec l'apprentissage de l'autodétermination. L'espoir est un ingrédient essentiel du rétablissement. Le rétablissement exige que chaque personne ait la chance d'aller mieux, à son propre rythme. L'approche du rétablissement demande aux gens ce qu'ils souhaitent et ce dont ils ont besoin pour grandir, et leur fournit les compétences et les soutiens pour y parvenir.<sup>99</sup>

Modifier la relation entre les personnes qui ont été étiquetées « malades mentales » et les autres peut également créer un terrain d'entente. Accepter la possibilité que quiconque d'entre nous peut subir une maladie mentale et que, comme le dit John Frank, médecin et directeur scientifique de l'Institut de la santé publique et des populations, nous « sommes tous à risque à des moments différents de notre vie »<sup>100</sup> contribue à supprimer le stigmate engendré par la distinction que nous avons faite entre « elles » et « nous ».

La voie de chaque personne vers le rétablissement est unique et ce qui favorise le rétablissement reflète les expériences et les préférences personnelles. Le rétablissement peut comporter des programmes en 12 étapes, le développement d'amitiés étroites, solidaires et mutuelles, un traitement intermittent ou permanent, la participation à des programmes de réadaptation sociale ou professionnelle, l'adhésion à des communautés spirituelles ou des réseaux de soutien dirigés par les consommateurs/réchappés et des groupes militants. Le pouvoir et la responsabilité doivent être partagés en engageant activement les consommateurs et les membres de la famille à titre de joueurs clés dans la planification de la santé mentale, la gouvernance organisationnelle, la conception du système, l'évaluation et la prestation des services.

Les systèmes axés sur le rétablissement reconnaissent que les concepts de rétablissement doivent être enseignés et doivent créer des débouchés éducationnels comme des ateliers et des conférences pour les responsables des politiques, les planificateurs, les professionnels, les consommateurs et les parents. Les consommateurs sont considérés comme des éducateurs du rétablissement. Un modèle de rétablissement garantirait qu'un pourcentage du financement est affecté à des initiatives et à des mécanismes de soutien dirigés par les consommateurs, comme des initiatives de soutien par les pairs, d'autoassistance et de développement économique, ainsi que des programmes de secours en cas de crise et de

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<sup>99</sup> Deegan, P. (1996) Recovery and the Conspiracy of Hope. 6<sup>e</sup> Conférence annuelle sur les services de santé mentale en Australie.

<sup>100</sup> A. Gordon, (2005), « Combating the stigma of mental disorders: New initiative to kick off mental health week », Toronto Star, 29 avril 2005.

services de relève. Il suppose que l'on reconnaisse que, pour être couronné de succès, le renforcement de la capacité des organismes de consommateurs et de parents à participer de manière soutenue et utile exige un financement adéquat à long terme, une formation en gestion et un soutien organisationnel.

## CHAPITRE 4: QUESTIONS D'ORDRE JURIDIQUE

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*La responsabilisation exige que le système de santé mentale soit conforme à la loi. —Jennifer Chambers<sup>101</sup>*

### 4.1 ACCÈS AUX RENSEIGNEMENTS PERSONNELS SUR LA SANTÉ

#### 4.1.1 Toile de fond

La question du droit à la protection de la vie privée des personnes atteintes de maladie mentale et de toxicomanie, et l'impact de ce droit sur les aidants membres de la famille, a été soulevée à maintes reprises par les témoins aux audiences publiques depuis que le Comité a entrepris ses travaux il y a plus de deux ans. Dans un précédent examen de cette difficile question, le Comité a fait remarquer ce qui suit :

Les inquiétudes relatives à l'observation stricte des règles en matière de protection des renseignements personnels et de confidentialité s'appliquent également aux familles des personnes atteintes de maladie mentale ou de toxicomanie. Sans la permission du patient, que ce dernier peut être incapable d'accorder en cas de maladie mentale ou de toxicomanie, un médecin ne peut pas communiquer les renseignements personnels le concernant à ses parents, ses frères et sœurs ou ses enfants, qui doivent en prendre soin<sup>102</sup>.

En ce qui concerne la protection des renseignements personnels et la confidentialité, le Comité est bien conscient que toute érosion des mesures de protection dans ces domaines peut avoir de graves conséquences sur la confiance que les patients placent dans ceux qui leur dispensent des soins. Toutefois, comme nous l'avons indiqué ci-dessus, les témoins nous ont déclaré que la stricte observance des règles relatives à la protection des renseignements personnels et à la confidentialité va parfois à l'encontre des intérêts des personnes dont la santé mentale est compromise. Il faut reconnaître les difficultés particulières que les témoins nous ont décrites lorsqu'on élabore, interprète et applique les règles en matière de protection des renseignements personnels et de confidentialité, afin que les prestataires de soins de santé et les aidants membres de la famille puissent donner aux patients l'appui dont ils ont parfois besoin<sup>103</sup>.

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<sup>101</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>102</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie. (Novembre 2004) Rapport 1 — Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada, Chapitre 11, Section 11.3, p. 238.

<sup>103</sup> *Ibid.*, Chapitre 11, Section 11.7, p. 246.

Le Comité était tellement préoccupé après la première série d'audiences publiques que, dans son troisième rapport provisoire, il a posé une série de questions dans le but d'obtenir des commentaires additionnels de la part du public. Notamment, il a demandé ceci :

Existe-t-il des systèmes de santé mentale comportant des procédures et des formulaires de consentement meilleurs et plus clairs pour la divulgation d'informations aux familles? Quels changements faudrait-il apporter aux règles pour faciliter la communication des renseignements concernant un malade à sa famille? Faut-il normaliser et uniformiser davantage les usages quant à la communication de renseignements personnels sur des personnes atteintes de troubles mentaux ou de toxicomanie<sup>104</sup>?

Au cours des consultations publiques poussées qui ont suivi, de nombreux commentaires et débats ont porté sur ce sujet et le Comité a pris connaissance des réactions de personnes atteintes de maladie mentale et des membres de leur famille. Sans surprise, aucun consensus clair n'a émergé.

À titre d'illustration, voici ce que Ron Carten, coordonnateur du Réseau pour la santé mentale de Vancouver-Richmond, qui possède une expérience directe de la maladie mentale, a déclaré :

*Au sujet des enfants, je ne crois pas que la confidentialité devrait aller jusqu'à exclure les parents. Les parents doivent savoir quelle est la situation de leurs enfants et ils ont le droit d'être informés sur leurs enfants.*

*Quant aux adultes, je pense qu'il faut traiter le patient en santé mentale, peu importe ses liens de parenté, comme une personne à part entière qui a ses droits et sa dignité et, par conséquent, en dépit de l'intérêt manifesté par des membres de la famille, le caractère confidentiel doit être maintenu<sup>105</sup>.*

Joan Nazif, du Comité consultatif des familles des Services de santé mentale de Vancouver, a émis l'opinion contraire :

*Les familles sont grandement préoccupées par l'accès à l'information relative à un de leurs membres qui est atteint d'une maladie mentale. Les membres de la famille ne veulent pas connaître le contenu des conversations entre le thérapeute et son patient, en revanche, ils ont besoin de connaître le diagnostic, le plan de traitement, les questions liées à la sécurité, afin d'être en mesure d'offrir le meilleur soutien possible.*

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<sup>104</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie. (Novembre 2004) Rapport 3 — Santé mentale, maladie mentale et toxicomanie : Problèmes et options pour le Canada, Chapitre 6, Section 6.5, p. 45.

<sup>105</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42471-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42471-f.htm?Language=F&Parl=38&Ses=1&comm_id=47)

[...]

*Maintenant, il y a des situations, j'en suis sûre, où les familles ne jouent pas un rôle thérapeutique pour l'individu. Nous sommes les membres d'une famille qui aime chacun de ses membres, et nous offrons notre appui à ma fille 24 heures par jour. Ce que je veux dire, c'est que je serai là pour elle tant que je vivrai<sup>106</sup>.*

Compte tenu de l'ensemble des témoignages et des opinions, le Comité n'est pas convaincu que la question de la confidentialité soit source de conflit uniquement entre les personnes atteintes de maladie mentale et les aidants membres de leur famille. En outre, le Comité ne croit pas que les mesures de protection du droit à la vie privée des personnes atteintes de maladie mentale actuellement prévues par la loi ne fonctionnent pas. Ceci ne veut pas dire qu'une réforme des lois régissant la protection de la vie privée n'est pas nécessaire mais plutôt que celle-ci ne devrait pas être considérée de façon isolée du débat plus général concernant la transformation du système de santé mentale en entier.

**Le Comité n'est pas convaincu que la question de la confidentialité soit source de conflit uniquement entre les personnes atteintes de maladie mentale et les aidants membres de leur famille. En outre, le Comité ne croit pas que les mesures de protection du droit à la vie privée des personnes atteintes de maladie mentale actuellement prévues par la loi ne fonctionnent pas.**

#### 4.1.2 Trouver un moyen de progresser

Il incombe que les droits des personnes atteintes de maladie mentale et de toxicomanie établis par la *Charte*, notamment le droit à l'égalité, soient respectés. Ces Canadiens malades sont des membres à part entière de la société. Les interrogations quant à leur capacité mentale ne peuvent servir de prétexte pour les priver, en tout ou en partie, de leurs libertés civiles ou des droits de la personne.

Ceci étant dit, le Comité n'est pas insensible à la situation des aidants membres de la famille. Bon nombre de ces personnes qui ont témoigné devant le Comité ont fait part de leur vif désir d'aider et de soutenir les proches au cours du processus de rétablissement. En fait, ce sont leurs arguments solides et éloquentes qui ont fait en sorte que cette question soit continuellement demeurée à l'avant-scène de nos travaux.

##### 4.1.2.1 Vie privée et âge requis pour consentir

Tout d'abord, en ce qui concerne le droit à la vie privée des enfants et des jeunes, les parents veulent être pleinement renseignés sur la santé de leurs enfants et ils ont besoin d'être informés. L'accès des aidants membres de la famille aux renseignements personnels sur la santé revêt de toute évidence une importance accrue lorsqu'il s'agit d'un enfant. Néanmoins, le Comité reconnaît que, avant d'atteindre l'âge de la majorité, certaines personnes peuvent être tout à fait capables de décider qui devrait avoir accès aux renseignements personnels sur leur santé et dans quelle mesure ces personnes devraient y avoir accès.

<sup>106</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47)

Étant donné le manque d'uniformité dans les aires de compétences au Canada relativement aux dispositions législatives sur la vie privée et compte tenu de la capacité variable des enfants et des jeunes à consentir à leur propre traitement, le Comité recommande ce qui suit :

- |   |   |
|---|---|
| 1 | <b>Que les gouvernements des provinces et des territoires fixent un âge uniforme auquel les jeunes sont considérés comme étant capables de consentir à la collecte, à l'utilisation et à la divulgation des renseignements personnels sur leur santé.</b> |
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#### 4.1.2.2 Le rôle des professionnels de la santé

Certains témoins ont laissé entendre que les professionnels de la santé n'en faisaient pas assez pour s'assurer que les lois existantes régissant l'accès aux renseignements personnels sur la santé étaient appliquées uniformément et dans leur pleine mesure. Par exemple, Brenda McPherson, coordonnatrice provinciale, Psychiatric Patient Advocate Services, Nouveau-Brunswick, a fait part de ce qui suit dans son témoignage :

**Nous devons au contraire faire en sorte que les médecins s'intéressent à la question et acceptent d'aborder le problème avec le fils, la fille ou la mère du patient pour offrir leur aide.**  
— Brenda McPherson

*Pour ce qui est du partage de l'information avec les parents, les professionnels de la santé doivent être mieux informés sur le rôle actif qu'ils doivent jouer dans l'obtention du consentement des patients. Il s'agit de demander au patient de signer un document dans lequel il donne à son médecin la permission de parler avec ses parents.*

*Je pense que nous avons tendance à trop dramatiser la question du consentement et qu'il faut cesser. Les professionnels de la santé doivent en comprendre l'importance. Il faut peut-être ouvrir la porte et nous demander comment nous devons informer les professionnels de la santé afin qu'ils comprennent et qu'ils soient plus conscients qu'il ne s'agit pas d'un manquement à l'éthique, que ça ne leur nuira pas en tant que professionnels mais que le défaut de le faire peut nuire à leurs clients.*

*[...] Il y a deux aspects à cela. D'abord, il faut que nos professionnels de la santé deviennent conscients de l'importance d'obtenir le consentement... Je ne crois pas qu'ils le demandent ni qu'ils envisagent de le faire. Je crois qu'ils s'en tiennent au statu quo : ils ne peuvent pas le faire, et s'en lavent les mains. [...] Nous devons au contraire faire en sorte que les médecins s'intéressent à la question et acceptent d'aborder le problème avec le fils, la fille ou la mère du patient pour offrir leur aide. Il*

*faut encourager les médecins à agir de la sorte, plutôt qu'ils s'avouent impuissants car liés par l'éthique*<sup>107</sup>.

Ses propos ont été repris par France Daigle, Programme de prévention du suicide, ministère de la Santé du Nouveau-Brunswick, qui a déclaré ceci :

*... la première chose que les gens disent, c'est toujours : « Je ne peux rien vous dire parce que c'est confidentiel ». Cependant, quand on est en présence d'une personne qui risque de se suicider, c'est bien beau de respecter la confidentialité, et nous le faisons, car nous avons un code d'éthique, mais qu'est-ce qui est le plus important? Il faut le faire savoir à la famille et aux autres membres de l'entourage.*

*Je trouve que, parfois, nous, dispensateurs de soins, membres de la famille ou professionnels, invoquons le prétexte de la confidentialité. Nous devons commencer à travailler ensemble*<sup>108</sup>.

Le Comité est d'avis que les professionnels de la santé ont un rôle important à jouer pour améliorer l'échange d'information entre les personnes souffrant de maladie mentale et les membres de leur famille. Par conséquent, le Comité recommande ce qui suit :

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| 2 | <b>Que les professionnels de la santé jouent un rôle actif dans la promotion des communications entre les personnes atteintes de maladie mentale et leur famille. Ceci consiste, entre autres, à demander aux personnes souffrant de maladie mentale si elles désirent partager les renseignements personnels sur leur santé avec leur famille, à leur remettre des exemplaires des formulaires de consentement requis et à les aider à les remplir.</b> |
|---|--|

Joan Nazif a proposé d'élargir encore davantage le rôle des professionnels de la santé. Elle a fait remarquer ceci :

*À l'instar de nombreuses autres provinces, nous avons notre propre loi sur l'accès à l'information et la protection de la vie privée, la FOIPPA, mais contrairement à d'autres provinces, nous avons la chance que cette loi soit assortie de lignes directrices. Ces lignes directrices,*

**Le Comité est d'avis que, en cas de danger clair, sérieux et imminent, les professionnels de la santé pourraient être tenus en droit de prévenir les tiers et, ainsi, protéger le patient. Toutefois, le Comité n'est pas d'avis que les professionnels de la santé devraient assumer le rôle d'arbitres quasi-judiciaires.**

<sup>107</sup> 11 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evf-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evf-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>108</sup> 11 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evf-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evf-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*rédigées par le ministère de la Santé de notre province, stipulent qu'un intervenant en matière de santé peut décider de communiquer de l'information à la famille ou à une autre tierce partie<sup>109</sup>.*

Le Comité est d'avis que, en cas de danger clair, sérieux et imminent, les professionnels de la santé pourraient être tenus en droit de prévenir les tiers et, ainsi, protéger le patient. Toutefois, le Comité n'est pas d'avis que les professionnels de la santé devraient assumer le rôle d'arbitres quasi-judiciaires entre les personnes atteintes de maladie mentale et les membres de leur famille ni de jouer le rôle de commissaire à la protection de la vie privée ou de juge pour l'interprétation de la loi régissant le droit au respect de la vie privée. Par conséquent, le Comité recommande ceci :

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|---|---|
| 3 | <p><b>Que les professionnels de la santé aient le pouvoir discrétionnaire de communiquer des renseignements personnels sur la santé, sans le consentement de l'intéressé, en cas de danger clair, sérieux et imminent afin de prévenir les tiers et de protéger le patient.</b></p> <p><b>Que ce pouvoir discrétionnaire soit régi par une norme juridique clairement définie dans la loi et sujet à examen par les commissaires à la protection de la vie privée et les tribunaux.</b></p> |
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#### **4.1.2.3 Subrogés et directives préalables**

Le Comité était préoccupé du fait que de nombreuses familles semblaient ne pas savoir que, souvent, les lois provinciales anticipent l'incapacité des personnes atteintes de maladie mentale et contiennent des dispositions précises visant à leur faciliter la communication de renseignements personnels

**La formulation de directives préalables et la nomination de subrogés permettraient de donner accès aux renseignements personnels sur la santé à la famille tant en préservant l'autonomie et la dignité des personnes atteintes de maladie mentale.**

sur la santé. Par exemple, aux termes de la loi ontarienne, une personne mentalement capable peut désigner un subrogé et lui accorder le droit d'accès aux renseignements personnels sur sa santé, en tout ou en partie. Les personnes ayant une expérience directe de la maladie mentale, comme Ron Carten, ont laissé entendre que cette façon de faire pourrait être une solution de remplacement à la diminution des mesures de protection de la vie privée :

*Eh bien, vous mettez en doute que la personne diagnostiquée d'une maladie mentale puisse prendre une décision. Il existe par exemple des directives préalables. La Representation Agreement Act de Colombie-Britannique prévoit cette possibilité, mais exclut explicitement les malades mentaux. Si ce droit était accordé aux gens qui ont une maladie*

<sup>109</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42470-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42470-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*mentale, ceux-ci pourraient nommer quelqu'un à l'avance qui serait chargé de prendre des décisions en leur nom quand ils n'en sont plus capables<sup>110</sup>.*

La formulation de directives préalables et la nomination de subrogés s'inscrivent dans un processus relativement simple. Si ces mesures étaient largement utilisées, elles permettraient de donner accès aux renseignements personnels sur la santé à la famille tant en préservant l'autonomie et la dignité des personnes atteintes de maladie mentale. Pour cette raison, le Comité recommande ceci :

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|---|--|
| 4 | <p><b>Que les gouvernements des provinces et des territoires donnent le pouvoir aux personnes capables mentalement, par le truchement de la loi, de désigner un subrogé et de donner des directives préalables concernant l'accès aux renseignements personnels sur leur santé.</b></p> <p><b>Que les dispositions de toute loi provinciale ayant pour effet d'interdire de donner des directives préalables concernant les décisions sur les soins de santé mentale soient abrogées.</b></p> <p><b>Que les gouvernements des provinces et des territoires offrent des formulaires et des trousseaux d'information expliquant la marche à suivre pour désigner un subrogé et donner des directives préalables.</b></p> <p><b>Que les gouvernements des provinces et des territoires offrent des services juridiques communautaires pour aider les personnes à désigner un subrogé et à donner des directives préalables.</b></p> <p><b>Que les gouvernements des provinces et des territoires réalisent des campagnes d'information publique pour informer les personnes atteintes de maladie mentale, et leur famille, concernant le droit de désigner un subrogé et de donner des directives préalables.</b></p> |
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#### **4.1.2.4 Comblant les lacunes**

Le Comité est conscient qu'il n'y aura pas de planification préliminaire dans tous les cas. Certaines personnes ne pourront peut-être pas prévoir qu'elles tomberont malades et, par conséquent, nommer un subrogé ou donner des directives préalables. Après tout, il n'est pas rare que des personnes, notamment les jeunes, meurent sans avoir pensé à la planification de leur succession et surtout sans un testament valide.

**Le mieux que nous puissions espérer, c'est d'offrir aux Canadiens et à leur famille la possibilité de planifier au cas où ils seraient frappés d'incapacité à l'avenir et, à défaut de quoi, leur offrir une deuxième possibilité.**

<sup>110</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42471-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42471-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Dans de tels cas, il est important qu'il existe un mécanisme légal pour combler les lacunes. Il est raisonnable de supposer que les personnes atteintes de maladie mentale voudraient et souhaiteraient que leur conjoint, leurs enfants, leurs parents ou d'autres membres de la famille prennent soin d'elles de la même manière qu'ils le feraient en cas de maladie physique imprévue. Il est aussi raisonnable de prévoir que les aidants membres de la famille devraient avoir accès à certains renseignements personnels sur la santé pertinents afin de mieux soigner le proche malade. Par conséquent, voici ce que le Comité recommande :

5	<p>Que, lorsqu'une personne reçoit un diagnostic de maladie mentale et est de ce fait considérée comme mentalement incapable, lorsqu'il n'y a pas d'antécédent de maladie mentale ni incapacité mentale, et lorsque aucun subrogé n'a été désigné et qu'aucune directive préalable n'a été donnée, la loi établisse une présomption en faveur de la communication des renseignements personnels sur la santé aux aidants membres de la famille du malade.</p> <p>Que les gouvernements des provinces et des territoires adoptent des lois uniformes établissant cette présomption.</p> <p>Que la loi précise un « ordre de préséance » pour les parents (c'est-à-dire, si la personne est mariée ou vit en union de fait, les renseignements sont communiqués à son conjoint ou à son conjoint de fait et, en l'absence d'un conjoint ou d'un conjoint de fait, à ses enfants, etc.).</p> <p>Que la loi précise les renseignements à communiquer, y compris le diagnostic, le pronostic, le plan d'intervention (y compris les options de traitement, le traitement prescrit et la gestion des effets secondaires), le niveau d'observation du régime de traitement et les questions de sécurité (par ex. risque de suicide).</p> <p>Que la loi interdise expressément la communication des documents de counselling.</p> <p>Que la loi oblige la personne qui communique les renseignements personnels sur la santé à informer la personne mentalement incapable, par écrit, de l'information qui a été communiquée et des personnes auxquelles cette information a été transmise.</p>
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Le Comité est conscient que cette solution n'est pas idéale et qu'il est peu probable que les familles qui prennent soin d'une personne atteinte de maladie mentale seront pleinement satisfaites. Cependant, il n'entre pas dans nos fonctions d'obliger les personnes atteintes de maladie mentale à prendre des décisions, quelles qu'elles soient.

Le mieux que nous puissions espérer, c'est d'offrir aux Canadiens et à leur famille la possibilité de planifier au cas où ils seraient frappés d'incapacité à l'avenir et, à défaut de quoi, leur offrir une deuxième possibilité. Si, toutefois, après avoir recouvré sa capacité mentale, une personne décide de ne pas partager les renseignements personnels sur sa santé

pertinents avec ses proches à partir de ce moment, le Comité comprend que la décision revient à la personne concernée.

## 4.2 CHARTE DES DROITS DU PATIENT

### 4.2.1 Toile de fond

Le Comité a examiné en long et en large les mesures nécessaires pour assurer que les patients reçoivent les soins et le soutien dont ils ont besoin. Dans un précédent rapport intitulé *La santé des Canadiens — Le rôle du gouvernement fédéral*, le Comité a avancé l'idée de recourir à une charte des droits du patient « comme moyen de faire respecter des délais d'attente maximums<sup>111</sup> ». Cette option a finalement été rejetée en faveur d'autres approches moins légalistes, mais l'idée n'a pas disparu pour autant.

Au cours des audiences publiques qui ont précédé la publication des rapports provisoires du Comité sur la santé mentale, la maladie mentale et la toxicomanie, un certain nombre de témoins ont soulevé dans ce nouveau contexte l'adoption possible d'une charte du patient. Le Comité a également noté la vision solide élaborée par le Groupe d'étude sur la mise en oeuvre de la réforme du système de santé mentale du district de Champlain en Ontario. Ainsi, ce groupe a préconisé une charte qui :

...ne se limiterait pas aux services de santé mentale, puisqu'elle engloberait également un vaste éventail de moyens de soutien sociaux. Voici, plus précisément, ce sur quoi elle porterait :

- services de santé mentale sûrs, garantis, fondés sur l'expérience clinique, opportuns, culturellement adaptés et pertinents aux besoins du patient;
- services et moyens de soutien incitant les personnes souffrant de maladie mentale ou de toxicomanie à se prendre en main et qui soient fondés sur les principes du rétablissement, de l'effort autonome ainsi que de la vie et du fonctionnement en autonomie;
- traitement respectueux des lois existantes (*Loi sur la santé mentale*, *Charte canadienne des droits et libertés*, etc.);
- respect de la vie privée et des choix informés<sup>112</sup>

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<sup>111</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie. (Avril 2002) *La santé des Canadiens — Le rôle du gouvernement fédéral*, Volume 5, Chapitre 2, Section 2.5, p. 60.

<sup>112</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie. (Novembre 2004) *Rapport 1 — Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, Chapitre 8, Section 8.2.7, pages 164-165.

#### 4.2.2 Consultation des intéressés

Compte tenu de l'intérêt suscité par une charte des droits des patients des services en santé mentale, le Comité a choisi d'examiner cette question plus à fond. Au cours de la deuxième consultation en ligne du Comité, les Canadiens ont été invités à se prononcer sur une « charte des droits des usagers-usagères » établie par la loi et à faire connaître leur opinion sur son contenu.

Les Canadiens ont dit appuyer l'adoption d'une charte des droits des patients établie par la loi mais cette idée suscitait un appui un peu moindre chez les membres de la famille et les fournisseurs de services que chez les personnes atteintes de maladie mentale<sup>113</sup>. De plus, l'inclusion de certains éléments a recueilli l'appui des répondants, par exemple :

1. le droit à des services en santé mentale et en toxicomanie d'une qualité au moins égale à celle des autres services de santé offerts à tous les Canadiennes et Canadiens,
2. le droit à un accès opportun à des services de santé mentale et de toxicomanie,
3. le droit à des services de santé mentale et de toxicomanie offerts dans la langue choisie par l'usager-usagère et prenant en compte la dimension culturelle,
4. le droit à une gamme adaptée de services médicaux et de services non médicaux en santé mentale et toxicomanie,
5. une protection contre l'expression publique de propos discriminatoires ou de points de vue qui constituent des préjugés à l'endroit des personnes atteintes de troubles mentaux ou de toxicomanie<sup>114</sup>.

Les résultats de la deuxième consultation en ligne ont été favorables mais la charte des patients proposée a quand même donné lieu à des critiques. Par exemple, deux participants anonymes ont écrit ceci :

*Juste ce dont nous avons besoin ... une autre charte ... un bout de papier qui sera vraiment utile! NON! Au lieu d'enrichir davantage les avocats et d'accroître la popularité des groupes d'activistes spécialisés qui intentent des poursuites pour leur propre plaisir, le gouvernement devrait peut-être envisager de financer suffisamment ces services. Voilà qui serait une idée nouvelle! —Anonyme*

*Le gouvernement fédéral ferait bien d'assurer l'application de l'actuelle Charte des droits et libertés plutôt que d'élaborer une autre charte pour des populations données. —Anonyme*

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<sup>113</sup> Ascentum Incorporated. (Juin 2005) Rapport sur la consultation en ligne par le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 40.

<sup>114</sup> *Ibid.*, p. 38.

### 4.2.3 Obstacles

Le Comité prend note de l'appui démontré à l'endroit d'une charte des patients dans la deuxième consultation en ligne mais il est également conscient des obstacles posés à l'application de celle-ci. Ces difficultés entrent dans deux grandes catégories.

**Le Comité prend note de l'appui démontré à l'endroit d'une charte des patients dans la deuxième consultation en ligne**

#### 4.2.3.1 Obstacles théoriques

Le Comité n'est pas à l'aise avec l'idée d'un régime juridique distinct pour les personnes atteintes de maladie mentale. À notre avis, si l'on enchâsse les droits d'un segment donné de la population dans un instrument juridique distinct, le groupe en question risque davantage d'être aliéné et stigmatisé. Ceci est particulièrement vrai si la charte des patients proposée lie les obligations ou les « responsabilités » aux droits qu'elle cherche à protéger.

**Le Comité est préoccupé par le fait qu'une charte des patients pourrait avoir comme conséquence involontaire la dilution, plutôt que l'augmentation, des mécanismes d'application existants.**

La *Charter of Adult and Family Rights and Responsibilities*<sup>115</sup> (charte des droits et des responsabilités des adultes et de la famille) permet de démontrer ce point. Cette charte consacre une section en entier à la « responsabilité » de maintenir une bonne hygiène personnelle. Elle se lit comme suit :

#### 8. Hygiène

- Portez une attention spéciale à votre hygiène. Une mauvaise hygiène est offensante pour autrui.
- Lavez-vous, brossez-vous les dents et lavez-vous les cheveux régulièrement.
- Si cela vous pose des difficultés, demandez de l'aide. Peut-être voudrez-vous en faire l'un de vos objectifs<sup>116</sup>.

Le Comité ne désire pas critiquer exagérément les efforts d'un groupe de citoyens soucieux mais il met en doute l'utilité d'une charte des patients qui établirait un lien entre la violation de droits constitutionnels, par exemple la protection de toute détention arbitraire, et le défaut de ne pas agir de façon « responsable » (par ex. le fait de ne pas se laver les cheveux).

De même, le Comité est préoccupé par le fait qu'une charte des patients pourrait avoir comme conséquence involontaire la dilution, plutôt que l'augmentation, des mécanismes d'application existants. Si un droit légal était inclus dans une charte des patients, il pourrait arriver que l'on achemine des plaintes vers d'autres organismes qui rendront une décision

<sup>115</sup> La charte des droits et des responsabilités des adultes et de la famille a été élaborée par le comité de la charte des droits et des responsabilités des adultes et de la famille, Cranbrook (Colombie-Britannique).

<sup>116</sup> Le comité de la charte des droits et des responsabilités des adultes et de la famille. (Mai 2003) — Charte des droits et des responsabilités des adultes et de la famille, p. 12.

plutôt que de recourir à des mécanismes d'application quasi judiciaires ou judiciaires assujettis à des critères juridiques uniformes.

La *Charte des droits des clients*<sup>117</sup> du Centre de toxicomanie et de santé mentale (CTSM) à Toronto est utilisée ici à des fins d'illustration. Ce document, à ne pas confondre avec la *charte des droits et des responsabilités des adultes et de la famille*, est un instrument exhaustif basé sur les droits qui, à notre avis, peut atteindre les objectifs prévus, à savoir promouvoir « ... la dignité et la valeur de toutes les personnes qui se prévalent des services offerts par le Centre de toxicomanie et de santé mentale<sup>118</sup> ». La difficulté, toutefois, tient au fait qu'elle s'immisce dans le domaine des droits légaux antérieurs.

Aux termes du paragraphe 6(4) de la *Charte des droits des clients*, « chaque client a le droit de consulter son dossier clinique sans difficulté excessive<sup>119</sup> ». La raison pour laquelle cette disposition est incluse dans la charte n'est pas claire parce que, en Ontario, la *Loi sur la protection des renseignements personnels sur la santé* établit :

...un processus structuré qui permet aux particuliers d'accéder aux renseignements personnels sur leur santé et de les rectifier, dans des délais précis, et leur confère le droit de porter plainte si leur demande d'accès ou de rectification a été refusée<sup>120</sup>.

Le Commissaire à l'information et à la protection de la vie privée/Ontario, qui dispose de vastes pouvoirs pour l'application de la Loi, statue sur les plaintes. De plus, la Loi prévoit des amendes pouvant atteindre 250 000 \$ susceptibles d'être imposées aux organisations qui commettent une infraction prévue par celle-ci. Le chevauchement inutile intrigue le Comité.

Le Comité croit fermement que tous les Canadiens devraient bénéficier de la même protection et des mêmes avantages en vertu de la loi, y compris le fait que leurs droits sont énoncés et appliqués de manière uniforme. Par conséquent, la mesure que nous préférons consiste à faciliter l'accès aux renseignements personnels sur la santé conformément aux procédures et aux critères énoncés dans les lois sur la protection de la vie privée existantes. C'est la raison pour laquelle la proposition voulant que les personnes atteintes de maladie mentale utilisent d'autres mécanismes de plainte nous rend mal à l'aise.

**La mesure que nous préférons consiste à faciliter l'accès aux renseignements personnels sur la santé conformément aux procédures et aux critères énoncés dans les lois sur la protection de la vie privée existantes. La proposition voulant que les personnes atteintes de maladie mentale utilisent d'autres mécanismes de plainte nous rend mal à l'aise.**

<sup>117</sup> La *Charte des droits des clients* a été élaborée par les clients, les familles et le personnel du Centre de toxicomanie et de santé mentale à Toronto (Ontario) et entérinée par le Conseil d'administration.

<sup>118</sup> Centre de toxicomanie et de santé mentale, *Charte des droits des clients*.

<sup>119</sup> *Ibid.*, Droit n° 6(4), p. 5.

<sup>120</sup> Commissaire à l'information et à la protection de la vie privée/Ontario. Questions fréquentes : *Loi sur la protection des renseignements personnels sur la santé* - Quels sont les droits des particuliers? [http://www.ipc.on.ca/scripts/index\\_.asp?action=31&P\\_ID=15371&N\\_ID=1&U\\_ID=0&LG\\_ID=2](http://www.ipc.on.ca/scripts/index_.asp?action=31&P_ID=15371&N_ID=1&U_ID=0&LG_ID=2).

Le Comité reconnaît que la *Charte des droits des clients* n'empêche pas les clients du CTSM de se prévaloir des mécanismes d'application dont fait état la *Loi sur la protection des renseignements personnels sur la santé*. Cependant, nous sommes préoccupés par le fait que les personnes qui choisissent cette voie seront considérées comme « difficiles » ou « chicanières ». De plus, nous nous demandons si des mécanismes de plainte internes, notamment en l'absence d'un règlement par une tierce partie et de sanctions clairement définies, donneront des résultats équivalents pour les plaignants.

#### **4.2.3.2 Obstacles pratiques**

Il a été proposé un certain nombre de solutions pour mettre en place une charte des droits des patients concernant les services en santé mentale, notamment de créer une loi canadienne sur la santé mentale, de modifier la *Loi canadienne sur les droits de la personne* et d'élaborer une loi distincte qui serait adoptée et par le Parlement et par les législatures provinciales et territoriales.

#### **4.2.3.3 Loi canadienne sur la santé mentale**

Une solution consisterait à mettre en place une Loi fédérale sur la santé mentale qui établirait les droits des personnes qui vivent avec la maladie mentale, en ce qui concerne les services en santé mentale. Cette solution pose toutefois un certain nombre de difficultés.

Le principal obstacle a trait à la division des pouvoirs dans la constitution canadienne. À quelques exceptions près, les provinces détiennent généralement la compétence en matière de santé, y compris sur les hôpitaux, la prestation directe de la plupart des services médicaux, la formation des médecins et d'autres fonctions connexes<sup>121</sup>. Les services en santé mentale relèvent principalement de la compétence des provinces.

En vertu du Transfert canadien en matière de santé (TCMS), le pouvoir de dépenser du gouvernement fédéral est utilisé pour influencer sur le système canadien d'assurance-maladie<sup>122</sup>. Ce même pouvoir est également utilisé pour fixer des normes nationales par le truchement de la *Loi canadienne sur la santé*, dont la raison d'être est « d'établir les conditions d'octroi et de versement d'une pleine contribution pécuniaire pour les services de santé assurés et les services complémentaires de santé fournis en vertu de la loi d'une province »<sup>123</sup>. La *Loi canadienne sur la santé* permet que la compensation pécuniaire à transférer en vertu du TCMS soit réduite dans deux cas; premièrement, lorsqu'une province autorise la surfacturation<sup>124</sup> ou l'imposition de frais modérateurs<sup>125</sup>; deuxièmement, si le régime d'assurance-santé ne répond

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<sup>121</sup> Young, M. (décembre 2000) *Le rôle fédéral dans le domaine de la santé et des soins de santé*. TIPS-59F, Service d'information et de recherches parlementaires, Bibliothèque du Parlement, Ottawa, p. 1.

<sup>122</sup> *Ibid.*, p. 2.

<sup>123</sup> *Loi canadienne sur la santé*, c. 6, art. 4.

<sup>124</sup> La surfacturation est définie dans la *Loi canadienne sur la santé* comme suit : « Facturation de la prestation à un assuré par un médecin ou un dentiste d'un service de santé assuré, en excédent par rapport au montant payé ou à payer pour la prestation de ce service au titre du régime provincial d'assurance-santé. »

<sup>125</sup> Les frais modérateurs sont définis dans la *Loi canadienne sur la santé* comme suit : « Frais d'un service de santé assuré autorisés ou permis par un régime provincial d'assurance-santé mais non payables, soit directement soit indirectement, au titre d'un régime provincial d'assurance-santé, à l'exception des frais imposés par surfacturation. »

pas aux critères d'octroi quant à la gestion publique, l'intégralité, l'universalité et la transférabilité.

Parallèlement, il importe de souligner que la *Loi canadienne sur la santé* ne vise pas les services prodigués dans un hôpital ou un établissement principalement destiné à des personnes souffrant de maladies mentales. Cette réalité a été soulignée par le docteur Sunil Patel, lorsqu'il s'est présenté devant le Comité à titre de président de l'Association médicale canadienne. Il a fait valoir que la *Loi canadienne sur la santé* devrait être modifiée de manière à inclure de tels services psychiatriques<sup>126</sup>.

Or le Comité estime qu'une telle modification serait surtout symbolique, pour deux raisons : premièrement, la plupart des établissements psychiatriques autonomes ont été fermés afin que les services en santé mentale soient offerts dans les hôpitaux où sont déjà fournis les services en santé physique; deuxièmement, les régimes provinciaux d'assurance-maladie couvrent peu ou pas du tout bon nombre des services essentiels aux personnes qui vivent avec la maladie mentale (p. ex., les services psychologiques ou les pharmacothérapies). Par conséquent, le Comité n'appuie pas une telle modification à la *Loi canadienne sur la santé*.

Il pourrait néanmoins être possible d'élaborer une Loi canadienne sur la santé mentale inspirée de la *Loi canadienne sur la santé*, c'est-à-dire de lier les transferts fédéraux à la conformité des gouvernements provinciaux ou territoriaux à certains principes guidant la prestation de services en santé mentale. Il est toutefois difficile d'imaginer la manière dont pourrait être contrôlée l'observance d'une telle loi, entre autres parce que les transferts aux provinces ne sont pas divisés en deux catégories : santé physique et santé mentale.

Également, il a été formulé à l'endroit de la *Loi canadienne sur la santé* un certain nombre de critiques qui illustrent quelques-unes des difficultés qui découleraient probablement d'une Loi canadienne sur la santé mentale. En 2002, la Vérificatrice générale a souligné que Santé Canada ne disposait toujours pas d'informations suffisantes pour déterminer la mesure dans laquelle les provinces et les territoires se conformaient aux critères et aux conditions de la *Loi canadienne sur la santé*<sup>127</sup>. La Vérificatrice générale se disait également troublée indisposée par les délais de résolution des cas de non-respect :

Santé Canada a tenté d'adopter une approche de non-ingérence pour administrer la *Loi*. Cette approche n'a toutefois pas permis de résoudre rapidement les problèmes liés au non-respect et à l'interprétation de la *Loi*. La majorité des cas de non-conformité relevés par Santé Canada au cours des dix dernières années sont demeurés en suspens pendant cinq ans ou plus<sup>128</sup>.

De plus, il importe de reconnaître que les sanctions prises en vertu de la *Loi canadienne sur la santé* ont trait aux frais modérateurs et à la surfacturation et que la déduction pour non-

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<sup>126</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie; (novembre 2004) Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, Chapitre 3, Section 3.4.1, p. 58.

<sup>127</sup> Rapport du Vérificateur général du Canada — Septembre 2002, Chapitre 3, *Santé Canada* — *L'appui fédéral à la prestation des soins de santé*, paragraphe 3.2.

<sup>128</sup> *Ibid.*, paragraphe 3.76.

conformité aux critères ou aux conditions de la Loi n'a jamais été utilisée. Étant donné que les questions touchant aux services en santé mentale tomberaient probablement sous le coup des grands critères de l'intégralité et de l'universalité en vigueur sous le régime de la *Loi canadienne sur la santé*, l'expérience passée nous laisse supposer que l'on ne ferait pas davantage respecter une loi inspirée de la *Loi canadienne sur la santé*.

Les difficultés et les préoccupations évoquées ci-dessus laissent supposer qu'il serait malavisé de s'inspirer de la *Loi canadienne sur la santé* pour établir une Charte des droits des patients.

**Les difficultés et les préoccupations évoquées laissent supposer qu'il serait malavisé de s'inspirer de la *Loi canadienne sur la santé* pour établir une Charte des droits des patients.**

#### **4.2.3.4 Modifier la *Loi canadienne sur les droits de la personne***

Une autre solution pour mettre en œuvre une Charte des droits des patients consisterait à modifier la *Loi canadienne sur les droits de la personne*, dont l'objet est énoncé à l'article 2 :

La présente loi a pour objet de compléter la législation canadienne en donnant effet, dans le champ de compétence du Parlement du Canada, au principe suivant : le droit de tous les individus, dans la mesure compatible avec leurs devoirs et obligations au sein de la société, à l'égalité des chances d'épanouissement et à la prise de mesures visant à la satisfaction de leurs besoins, indépendamment des considérations fondées sur la race, l'origine nationale ou ethnique, la couleur, la religion, l'âge, le sexe, l'orientation sexuelle, l'identité ou l'expression sexuelle, l'état matrimonial, la situation de famille, la déficience ou l'état de personne gracée<sup>129</sup>.

Voici des actes discriminatoires en vertu de la Loi :

- le fait, pour un fournisseur de biens, de services, d'installations ou de moyens d'hébergement destinés au public d'en priver un individu sur un motif de distinction illicite (art. 5);
- le fait de refuser d'employer ou de continuer d'employer un individu en raison d'un motif de distinction illicite (art. 7);
- le fait de publier ou d'exposer en public des affiches, des écriteaux, des insignes, des emblèmes, des symboles ou autres représentations qui expriment ou suggèrent des actes discriminatoires ou en encouragent ou visent à en encourager l'accomplissement (art. 12);
- le fait de communiquer des messages de haine (art. 13).

La *Loi canadienne sur les droits de la personne* s'applique uniquement aux domaines de compétence fédérale. Par conséquent, elle ne serait pas le bon instrument pour exiger des modifications aux lois provinciales en santé mentale ou pour améliorer les services aux

<sup>129</sup> L.R.C. (1985), c. H-6, art. 2.

personnes atteintes de maladie mentale. La Loi s'applique toutefois aux services en santé aux Premières nations et aux Inuits, aux anciens combattants et aux délinquants sous responsabilité fédérale, des populations qui reçoivent certains services de santé du gouvernement fédéral.

Hormis l'obligation faite aux fournisseurs de services sous compétence fédérale d'éviter toute discrimination dans la prestation de leurs services, aucune disposition de la *Loi canadienne sur les droits de la personne* ne précise la manière dont des services donnés doivent être fournis.

L'on pourrait modifier la loi afin d'y incorporer des références à la prestation de services. Cependant, une telle modification aurait une application limitée, étant donné qu'elle s'appliquerait uniquement à des populations particulières et dans des circonstances précises.

**La Loi canadienne sur les droits de la personne s'applique uniquement aux domaines de compétence fédérale. Par conséquent, elle ne serait pas le bon instrument pour exiger des modifications aux lois provinciales en santé mentale ou pour améliorer les services aux personnes atteintes de maladie mentale.**

#### ***4.2.3.5 Créer une loi distincte qu'adopteraient le Parlement et les législatures provinciales et territoriales***

Étant donné que les gouvernements provinciaux sont compétents en matière de santé (à l'exception des lois qui déclarent le droit à des services en santé mentale et d'autres groupes de populations dont le gouvernement fédéral est responsable), une loi adoptée par le Parlement se limiterait vraisemblablement à des transferts pécuniaires aux provinces, à la condition que celles-ci respectent certains critères, à la manière connue de la *Loi canadienne sur la santé*.

**L'élaboration d'une loi-type harmonisée qui pourrait être adoptée par les provinces et les territoires semblerait être la solution la plus susceptible de conduire à la création d'une charte des droits des personnes atteintes de maladie mentale. Or, vu les arguments avancés par le Comité contre la mise en place d'un régime distinct pour la santé mentale, cela n'est pas une piste qu'il recommanderait de suivre.**

Le gouvernement fédéral pourrait cependant inviter les provinces et les territoires à participer à un processus d'examen des lois existantes en matière de santé mentale. Cet examen aurait pour but d'élaborer une loi-cadre établissant des droits précis à des services en santé mentale qui pourrait être adoptée par les gouvernements provinciaux et territoriaux et par le gouvernement fédéral, pour les populations dont il est responsable. Un tel examen fédéral-provincial-territorial des mesures législatives pourrait s'inscrire dans la Conférence annuelle des ministres fédéral, provinciaux et territoriaux de la Santé.

On pourrait également proposer que la Conférence pour l'harmonisation des lois au Canada élabore une loi-type établissant les droits uniformes des consommateurs d'obtenir des services en santé mentale. En 1987, la Conférence a appuyé une Loi uniforme sur la santé mentale, élaborée afin que des lois provinciales n'enfreignent pas la *Charte canadienne des droits et libertés*.

La Conférence pour l'harmonisation des lois au Canada possède une section pénale et une section civile; elle a été chargée d'harmoniser les lois des provinces et des territoires et, le cas échéant, celles du gouvernement fédéral aussi. La section civile réunit des avocats et des

analystes s'occupant des politiques gouvernementales, des avocats du secteur privé ainsi que des personnes chargées de la réforme du droit. Elle examine les domaines dans lesquels il serait avantageux d'harmoniser les lois provinciales et territoriales<sup>130</sup>. Après avoir fait l'examen d'un domaine et rédigé un projet de loi, la section civile l'adopte et recommande son édicition par toutes les autorités compétentes du Canada.<sup>131</sup>

Comme nous l'avons vu plus haut, il est pratiquement certain que les provinces et les territoires réfuteraient une loi fédérale établissant les droits des personnes atteintes de maladie mentale à des services en santé mentale. Comme nous l'avons vu lors de l'analyse de la *Loi canadienne sur la santé*, la solution consistant à faire des paiements de transfert moyennant le respect de certains critères relatifs aux services en santé mentale pose des difficultés. L'élaboration d'une loi-type harmonisée qui pourrait être adoptée par les provinces et les territoires semblerait être la solution la plus susceptible de conduire à la création d'une charte des droits des personnes atteintes de maladie mentale. Or, vu les arguments avancés par le Comité contre la mise en place d'un régime distinct pour la santé mentale, cela n'est pas une piste qu'il recommanderait de suivre.

#### 4.3 LES DISPOSITIONS DU *CODE CRIMINEL* RELATIVES AUX TROUBLES MENTAUX

##### 4.3.1 Toile de fond

La partie XX.1 du *Code criminel* établit un régime exhaustif indépendant pour les personnes accusées qui sont jugées inaptes à subir leur procès ou qui bénéficient d'un verdict de non-responsabilité criminelle pour cause de troubles mentaux. Bien que cela ne fut pas son intention, le Comité s'est vu attiré dans le débat récent sur ce régime. Étant donné que ce régime a fait l'objet récemment d'un examen et d'une modification par le Parlement, nos commentaires se limiteront aux questions qui n'ont pas été résolues par l'adoption du projet de loi C-10<sup>132</sup>.

##### 4.3.2 Pouvoir des Commissions d'examen de rendre une ordonnance d'évaluation

Les commissions d'examen ont deux fonctions principales. Premièrement, lorsqu'une personne accusée est jugée par un tribunal inapte à subir son procès :

**L'information requise par les membres de la commission pour rendre une décision éclairée n'est pas toujours disponible.**

... il peut au départ ordonner uniquement la détention dans un hôpital ou la libération conditionnelle, mais non la libération inconditionnelle. À chaque audience de révision de la décision, la commission d'examen doit décider si l'accusé est devenu apte à subir son procès, auquel cas elle doit le renvoyer devant le tribunal. Si le tribunal conclut que l'accusé est devenu apte à subir son procès, ce dernier peut alors avoir lieu. Si l'on conclut que

<sup>130</sup> Site Web de la Conférence pour l'harmonisation des lois au Canada, <http://www.chlc.ca/fr/civil>.

<sup>131</sup> *Ibid.*

<sup>132</sup> *Loi modifiant le Code criminel (troubles mentaux) et modifiant d'autres lois en conséquence*, L.C. 2005, c. 22.

l'accusé est toujours inapte, celui-ci demeure assujéti à d'autres audiences de la commission d'examen<sup>133</sup>.

Une commission d'examen peut également recommander qu'une cour tiennne une enquête lorsqu'une personne ne pose pas de risque significatif pour le public et a peu de chance de jamais être apte à subir un procès. Une telle enquête peut aboutir à un sursis de procédures.

**Le fait que quelqu'un ait examiné les inaptes et ait donné un avis au cours des 12 derniers mois sur leur inaptitude n'est pas pertinent parce que l'inaptitude est une chose qui fluctue avec l'état clinique du patient. Elle peut changer de jour en jour, d'heure en heure. Donc, limiter le pouvoir de la Commission d'ordonner une évaluation comme on le fait dans le projet de loi est inutilement restrictif.**

— Juge Schnneider

Deuxièmement, lorsqu'un tribunal rend un verdict de non-responsabilité criminelle pour cause de troubles mentaux,

... il peut rendre une des trois décisions suivantes : la libération inconditionnelle, la libération avec conditions (autorisation de vivre dans la collectivité, à certaines conditions) ou la détention dans un hôpital (avec ou sans conditions). Le tribunal peut aussi, et le fait très souvent, laisser à la commission d'examen du gouvernement provincial ou territorial concerné le soin de décider. Toute décision autre que la libération inconditionnelle doit être révisée chaque année par la commission d'examen jusqu'à ce que celle-ci décide que l'accusé ne présente pas un risque important pour la sécurité du public et lui accorde alors sa libération inconditionnelle<sup>134</sup>.

Dans tous les cas, la loi exige que la commission d'examen impose la décision la moins restrictive. Cependant, le Comité a été sensibilisé au fait que l'information requise par les membres de la commission pour rendre une décision éclairée n'est pas toujours disponible. Le juge Schneider, président suppléant de la Commission d'examen de l'Ontario et de la Commission d'examen du Nunavut, a déclaré ce qui suit lors de son témoignage :

*... parce que les tribunaux prennent rarement une décision initiale quand on conclut que la personne est inapte à subir son procès ou qu'elle n'est pas criminellement responsable, et qu'ils s'en remettent alors à la Commission... Laisser la Commission d'examen sans le pouvoir, dans l'esprit de Winko, d'ordonner une évaluation serait tout à fait contraire au raisonnement de la Cour suprême.*

*Il me semble évident que le texte a été rédigé par quelqu'un qui ne comprenait pas comment fonctionne le système. Il y a souvent un rapport qui a été produit dans les 12 derniers mois. La question est savoir s'il porte bien sur les questions au sujet desquelles nous serons appelés à prendre une décision.*

<sup>133</sup> Raaflaub, W. (juin 2005) Dispositions du *Code criminel* relatives aux troubles mentaux, Service d'information et de recherche parlementaires, Bibliothèque du Parlement, Ottawa.

<sup>134</sup> *Ibid.*

*[...] Le rapport joint à la mise en accusation porte normalement sur l'aptitude à subir le procès ou sur la responsabilité criminelle, pas sur le choix de la solution la moins onéreuse et la moins restrictive, ce qui est précisément ce que doit décider la Commission<sup>135</sup>.*

Le projet de loi C-10 ayant été adopté, les commissions d'examen peuvent maintenant ordonner des évaluations quand un rapport d'évaluation n'est pas disponible ou qu'aucune évaluation n'a été réalisée au cours des 12 derniers mois<sup>136</sup>. Toutefois, comme le souligne le juge Schneider :

**Le Comité est convaincu par les arguments présentés de la nécessité d'accroître les pouvoirs des commissions d'examen.**

*En ce qui concerne les inaptes, le fait que quelqu'un les ait examinés et ait donné un avis au cours des 12 derniers mois sur leur inaptitude n'est pas pertinent parce que l'inaptitude est une chose qui fluctue avec l'état clinique du patient. Elle peut changer de jour en jour, d'heure en heure. Donc, limiter le pouvoir de la Commission d'ordonner une évaluation comme on le fait dans le projet de loi est inutilement restrictif.*

*Je pense qu'il aurait suffi de modifier légèrement le texte de l'article 672.11 en ajoutant « ou commission d'examen » après le mot « cour ». C'était la solution la plus simple<sup>137</sup>.*

Les tribunaux ont le pouvoir d'ordonner une évaluation à n'importe quelle étape des procédures à l'endroit de l'accusé. Le Comité est convaincu par les arguments présentés de la nécessité d'accroître les pouvoirs des commissions d'examen et recommande par conséquent :

- |   |  |
|---|--|
| 6 | <b>Que le <i>Code criminel</i> soit modifié de manière à conférer aux commissions d'examen les pouvoirs dont disposent déjà les tribunaux pour ce qui est d'ordonner une évaluation de la santé mentale.</b> |
|---|--|

#### 4.3.3 Pouvoir de la Commission d'examen d'ordonner un traitement

Les commissions d'examen n'ont pas le pouvoir d'ordonner qu'une personne accusée atteinte de troubles mentaux suive un traitement. Les tribunaux, en revanche, sont habilités à le faire par le *Code criminel*, dans des circonstances très limitées. Dans son témoignage devant le Comité, le juge Schneider a fait valoir ce qui suit.

<sup>135</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42201-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42201-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>136</sup> *Loi modifiant le Code criminel (troubles mentaux) et modifiant d'autres lois en conséquence*, L.C. 2005, c. 22., art. 3.

<sup>137</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Le plus gros problème du projet de loi, à part la possibilité d'ordonner des évaluations, concerne la possibilité pour la Commission de traiter l'accusé comme une personne inapte. Nous faisons cela de manière très agressive à la Cour de la santé mentale parce que nous avons des praticiens qui connaissent très bien la législation et qui savent comment l'appliquer mais, si vous sortez de ce petit domaine, vous constaterez que les ordonnances de traitement ne proviennent généralement pas du tribunal, ce qui signifie que l'accusé est jugé inapte par la Commission d'examen provinciale ou territoriale et qu'il reste sous sa juridiction jusqu'à ce qu'il devienne apte à subir son procès.*

**Les commissions d'examen n'ont pas le pouvoir d'ordonner qu'une personne accusée atteinte de troubles mentaux suive un traitement. Les tribunaux, en revanche, sont habilités à le faire par le Code criminel, dans des circonstances très limitées.**

*Si la Commission n'a pas la possibilité d'ordonner un traitement, comme le tribunal peut le faire en vertu de l'article 672.58, cela signifie que la province ou le territoire où réside l'accusé dépend de la législation civile locale pour pouvoir le faire traiter. Donc, vous avez une personne inapte qui restera dans le système 3, 4 ou 5 fois plus longtemps que si la Commission avait le pouvoir d'ordonner qu'elle soit traitée pendant une période pouvant atteindre 60 jours comme les tribunaux peuvent le faire en vertu de .58.*

**Le Comité a entendu le témoignage de nombreuses personnes atteintes de maladie mentale qui s'opposent vigoureusement à l'intervention psychiatrique forcée.**

*Si la Commission — qui, comme vous le savez, est composée d'experts — avait les mêmes pouvoirs que les tribunaux en vertu de .58, vous constateriez que les personnes inaptes resteraient beaucoup moins longtemps dans le système. Nous recommandons vigoureusement cette solution mais elle a à peine été prise en considération<sup>138</sup>.*

La question du traitement involontaire est très controversée. Le Comité a entendu le témoignage de nombreuses personnes atteintes de maladie mentale qui s'opposent vigoureusement à l'intervention psychiatrique forcée. Leur message était clair : le traitement imposé porte grandement atteinte à l'autonomie et à la dignité des personnes touchées :

*En plus des infractions de nature criminelle dont ils sont victimes, les patients du système de santé mentale sont aussi privés de leurs droits fondamentaux, de façon plus constante. Nous avons droit à une certaine protection devant la loi; ce droit est constamment violé.*

<sup>138</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Parlons par exemple du consentement éclairé. Étude après étude, les chercheurs montrent que peu d'utilisateurs sont renseignés sur les effets indésirables des médicaments psychotropes qu'on leur prescrit. Le droit correspondant au traitement le moins restrictif possible est fréquemment violé. Le droit de refuser un traitement correspond maintenant à un exercice d'évaluation de la compétence d'un patient du système de santé mentale qui ose refuser le traitement qu'on lui offre. — Jennifer Chambers<sup>139</sup>*

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*Si les traitements psychiatriques étaient efficaces et parvenaient à soulager la souffrance, notre système de santé ne serait pas dans la situation de crise qu'on lui connaît actuellement. Les gens adoreraient leurs médecins. Nous en sommes venus à imposer les traitements psychiatriques parce que les patients, trop souvent, ne se sentent pas mieux, ou parce qu'ils en viennent à détester les médicaments et leurs terribles effets secondaires.*

*... Il suffit d'un seul traitement imposé qui ne donne aucun résultat pour perdre la confiance d'une patiente, pour ancrer à jamais ses craintes, amplifiées. C'est une question cruciale pour la grande majorité des patients et des anciens patients que j'ai interrogés. Beaucoup ont été terrifiés par le système de santé. — Rob Wipond<sup>140</sup>*

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*On m'a offert le choix d'une électroconvulsothérapie en échange d'une libération précoce pour me forcer à signer le formulaire de consentement. À mes yeux, ce n'est pas un consentement, c'est de la coercition. Beaucoup d'aspects sont « volontaires », mais il arrive souvent que nous donnions notre consentement de façon involontaire. C'est comme si on m'avait mis un fusil sur la tempe pour me faire signer une cession de biens. On ne pourrait pas dire que j'ai donné mon consentement — c'est pourtant ce que font les médecins avec les patients.*

*[...]*

*Un psychiatre m'a déjà appelée chez moi pour me dire que je devais suivre ses indications, c'est-à-dire ajouter une pilule à mon cocktail médicamenteux déjà bien garni — je prenais quatre médicaments différents à fortes doses. Il m'a dit que si je refusais de me conformer, il*

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<sup>139</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42200-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/42200-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>140</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*m'enverrait la police, qui me traînerait à l'hôpital menottes aux poignets. C'est exactement ce qu'il m'a dit. Je me portais tout à fait bien à ce moment. — Francesca Allan<sup>141</sup>*

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*J'aimerais maintenant citer le directeur de l'Organisation mondiale de la santé qui a officiellement déclaré que le monde est au bord d'une crise en matière de droits de la personne et de santé mentale; il a notamment fait l'observation suivante, qui est très révélatrice :*

*Il y a violation des droits de la personne non seulement quand on refuse l'accès au traitement; de plus, et souvent, le traitement en soi constitue une violation des droits de la personne...*

*J'aimerais que vous y réfléchissiez. Tout cela pour dire que nous avons tendance à nous précipiter vers les solutions les plus coûteuses plutôt que d'écouter les intéressés nous dire ce dont ils ont besoin. Cela ne devrait pas être compliqué, mais, pour une raison quelconque, nous compliquons les choses. — Eugene LeBlanc<sup>142</sup>*

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*...vous ne pouvez pas imaginer à quel point cela m'a horripilé — à la lecture de l'exposé de la société de schizophrénie, qu'il est recommandé de retirer aux patients de psychiatrie légiste le droit de refuser un traitement en vertu du Code criminel. — Randy Pritchard<sup>143</sup>*

À la lumière de ces témoignages et d'autres communications, le Comité a des réserves au sujet du traitement involontaire, malgré que cela peut être nécessaire dans de rares cas. Nous reconnaissons que le fait de forcer des personnes à se soumettre à une intervention psychiatrique en l'absence de leur consentement ou du consentement des personnes habilitées à prendre des décisions à leur place a des conséquences réelles et profondes sur leur autonomie et leur dignité. De plus, une telle intervention pourrait enfreindre leurs droits en vertu de la *Charte canadienne des droits et libertés*.

Cela dit, les pouvoirs conférés aux tribunaux par le *Code criminel* permettent le traitement involontaire dans des circonstances très limitées. Un tribunal peut rendre une décision de traitement à la

**Nous reconnaissons qu'il importe et qu'il est urgent de réduire la période pendant laquelle des personnes jugées inaptes à subir leur procès demeurent dans le système.**

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<sup>141</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>142</sup> 11 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>143</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

demande d'un procureur dans le seul but de rendre une personne atteinte de troubles mentaux apte à subir son procès. Des preuves médicales doivent être produites, la décision est limitée à 60 jours et elle ne peut prescrire ni la psychochirurgie ni l'électroconvulsothérapie. De plus, l'accusé a le droit de contester la décision concernant le traitement.

Nous prenons acte des objections à l'intervention psychiatrique forcée, présentées au Comité par des personnes atteintes de maladies mentales et nous les respectons. Cependant, nous reconnaissons également qu'il importe et qu'il est urgent de réduire la période pendant laquelle des personnes jugées inaptes à subir leur procès demeurent dans le système. La décision suivante n'a pas été prise à la légère ni avec facilité. Cependant, la nature particulière de la décision concernant un traitement, combinée à la brève limite de temps, à l'interdiction de certains thérapies très invasives et aux garanties intégrées aux procédures donnent au Comité les assurances voulues. Par conséquent, nous recommandons :

- |   |   |
|---|---|
| 7 | <b>Que le <i>Code criminel</i> soit modifié de manière à conférer aux commissions d'examen les pouvoirs dont disposent déjà les tribunaux pour ce qui est d'ordonner un traitement.</b> |
|---|---|

#### 4.3.4 Aptitude à recevoir une sentence

Actuellement, il existe une faille dans la loi en ce qui concerne l'aptitude à subir son procès. Cette faille se manifeste lorsqu'une personne devient inapte *après* qu'un verdict est rendu. Autrement dit, cette personne n'est pas « inapte à subir son procès » mais bien « inapte à recevoir une sentence ». Le juge Schneider explique la situation en ces termes :

**Actuellement, il existe une faille dans la loi en ce qui concerne l'aptitude à subir son procès. Cette faille se manifeste lorsqu'une personne devient inapte après qu'un verdict est rendu.**

*L'autre problème majeur du projet de loi C-10, je crois, est que l'on pas modifié la définition de l'inaptitude à subir le procès de façon à y inclure la période allant jusqu'à la fin du processus sentenciel. Je pense que l'on a conservé la définition qui dit que c'est jusqu'à la fin du verdict, ce qui laisse un vide juridique dans les cas où l'accusé devient inapte après le verdict mais avant la sentence.*

*Dans l'arrêt Balliram de la Cour supérieur de l'Ontario, le juge McWatt a interprété l'article 2 en élargissant la définition de l'inaptitude à subir le procès. Nous avions espéré que le législateur s'en inspire mais il ne l'a pas fait<sup>144</sup>.*

<sup>144</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Ces préoccupations sont reprises par le juge Carruthers, président de la Commission d'examen de l'Ontario, qui a déclaré ceci lors de son témoignage :

*En pratique, il arrive souvent qu'une personne ait décompensé après le verdict, par exemple en attendant une demande de déclaration de délinquant dangereux. Vous êtes alors coincé car la personne est inapte à recevoir une sentence mais elle a été condamnée, et il est complètement absurde de ne pas étendre la définition, comme le propose Richard, de « verdict » à « sentence », ce qui réglerait tout le problème<sup>145</sup>.*

Cette question n'a pas été abordée par le projet de loi C-10 mais elle a été soulevée et commentée par Irwin Cotler, ministre de la Justice et Solliciteur général du Canada, qui s'est présenté devant le Comité sénatorial permanent des affaires juridiques et constitutionnelles pour s'exprimer sur le projet de loi :

**Le Comité est préoccupé par le fait que le Code criminel n'offre pas de moyen de traiter les personnes reconnues coupables qui deviennent incapables à recevoir une sentence après qu'un verdict a été rendu.**

*En ce qui concerne la question de l'aptitude à se voir infliger une peine, puisqu'on en a parlé, le projet de loi C-10 ne comporte pas de modification prévoyant un verdict d'incapacité à se voir infliger une peine ou une ordonnance d'évaluation au moment de la détermination de la peine. Cette question très importante devra faire l'objet d'études et de consultations approfondies. C'est pourquoi j'en fais part à votre comité.*

*Les modifications précises susceptibles de s'imposer touchent autant aux principes en matière de détermination de la peine qu'aux règles de droit régissant les personnes souffrant de troubles mentaux. Le ministère de la Justice a demandé la réalisation de recherches universitaires sur cette question dont les résultats donnent à penser que l'incapacité au moment de la détermination de la peine exige une conceptualisation ou un test d'aptitude distinct et des conséquences différentes de celles découlant du verdict d'incapacité à subir son procès.*

*Bien que je reconnaisse qu'il faut procéder à un examen de cette question, nous n'avons pas inclus de modifications précises dans le projet de loi C-10. On pourrait envisager des modifications à ce sujet dans un prochain projet de loi modifiant le droit criminel, après examen et consultation, de concert avec les ministres provinciaux et territoriaux responsables de la justice, à qui nous en avons parlé<sup>146</sup>.*

<sup>145</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>146</sup> 13 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/lega-f/09eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=11](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/lega-f/09eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=11).

Le Comité est préoccupé par le fait que le *Code criminel* n'offre pas de moyen de traiter les personnes reconnues coupables qui deviennent inaptes à recevoir une sentence après qu'un verdict a été rendu. Toutefois, étant donné la complexité de la question et le fait que le gouvernement du Canada prend des mesures pour la résoudre, nous considérons qu'il serait prématuré de faire une proposition précise à ce moment-ci; nous recommandons plutôt ce qui suit :

- |   |  |
|---|--|
| 8 | <p>Que le gouvernement du Canada, en consultant les ministres provinciaux et territoriaux de la Justice, élaborent des projets de modifications au <i>Code criminel</i> afin de résoudre la question des personnes reconnues coupables qui deviennent inaptes à se voir infliger une peine après que le verdict a été rendu.</p> <p>Que ces modifications soient soumises au Parlement dans l'année qui suivra le dépôt du présent rapport au Sénat.</p> |
|---|--|



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First Session  
Thirty-ninth Parliament, 2006

Première session de la  
trente-neuvième législature, 2006

## SENATE OF CANADA

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## SÉNAT DU CANADA

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*Proceedings of the Standing  
Senate Committee on*

*Délibérations du Comité  
sénatorial permanent des*

# Social Affairs, Science and Technology

# Affaires sociales, des sciences et de la technologie

*Chair:*  
The Honourable MICHAEL KIRBY

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*Président :*  
L'honorable MICHAEL KIRBY

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Monday, May 8, 2006

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Le lundi 8 mai 2006

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Issue No. 2  
Volume 2 of 5

Fascicule n° 2  
Volume 2 de 5

SECOND REPORT OF THE COMMITTEE  
(Final report on mental health,  
mental illness and addiction entitled:  
*OUT OF THE SHADOWS AT LAST*  
*Transforming Mental Health, Mental Illness  
and Addiction Services in Canada —  
Part III, Chapters 5, 6, 7 and 8)*

---

DEUXIÈME RAPPORT DU COMITÉ  
(Rapport final sur la santé mentale,  
la maladie mentale et la toxicomanie intitulé :  
*DE L'OMBRE À LA LUMIÈRE*  
*La transformation des services concernant la santé mentale,  
la maladie mentale et la toxicomanie au Canada —  
partie III, chapitres 5, 6, 7 et 8)*

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THE STANDING SENATE COMMITTEE  
ON SOCIAL AFFAIRS, SCIENCE  
AND TECHNOLOGY

The Honourable Michael Kirby, *Chair*

The Honourable Wilbert J. Keon, *Deputy Chair*

and

The Honourable Senators:

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Cordy	(or Comeau)
Eggleton, P.C.	Pépin
Fairbairn, P.C.	Trenholme Counsell

\*Ex officio members

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## PART III

# Service Organization and Delivery



## CHAPTER 5: TOWARD A TRANSFORMED DELIVERY SYSTEM

### 5.1 CONSENSUS ON THE DIRECTION FOR MENTAL HEALTH REFORM

Chapter 3 of this report described the Committee's underlying vision of how a transformed mental health system should be organized. At the core of this vision is a recovery-oriented, primarily community-based, integrated continuum of care.

**At the core of this vision is a recovery-oriented, primarily community-based, integrated continuum of care.**

In the course of its hearings, the Committee was pleased to learn that this vision reflects a strong national consensus on the broad outlines of what a transformed mental health system should look like. This consensus of so many of the key "players," providers and consumers alike, provides a strong springboard from which to pursue transformation of the way in which mental health services and supports are organized and delivered.<sup>147</sup>

In some jurisdictions, the goal of establishing a recovery-oriented, community-based, integrated continuum of care that places people living with mental illness at its centre has been in effect for some time. For example, in October 1988, the Government of New Brunswick created a Mental Health Commission with a mandate to reform mental health delivery. The Commission completed its work in 1996, creating a province-wide mental health delivery system inspired by a vision that aligns closely with that the Committee has outlined.

**Three key elements must be part of a transformed mental health system: the system must be recovery-oriented and person-centred; it must be predominantly community-based; and it must be integrated across the full continuum of care and across all age groups.**

Table 5.1 presents brief excerpts from documents produced during the past few years that demonstrate the pursuit of a similar approach to mental health reform across the country. It contains direct quotes from each report referring to three key elements that must be part of a transformed mental health system: the system must be recovery-oriented and person-

<sup>147</sup> As indicated in Chapter 3, the Committee has not been able to devote as much attention to substance use issues as it intended when it embarked on its study of "mental health, mental illness and addiction." The Committee recognizes that in previous decades, services for the two types of disorder were administered separately; they developed divergent treatment philosophies, used different terminology and constituted different "cultures" that were often in conflict. However, the limitations of this report with respect to substance use issues means that the Committee has been unable to examine fully the similarities and differences in approach in the mental health and substance use fields. Although some examples are drawn from the substance use sector, the main thrust of this chapter is the transformation of the organization and delivery of mental health services and supports. It would clearly not be appropriate for the Committee to assume that conclusions it has reached after carefully considering the mental health evidence necessarily apply with respect to substance use issues. Some may apply, but the Committee has attempted to avoid any unwarranted assumptions in this regard.

centred; it must be predominantly community-based; and it must be integrated across the full continuum of care and across all age groups. The last row in the Table contains excerpts from a recent British Columbia document that focuses on transforming services to address substance use and addiction problems, highlighting the same three key elements.

The policy consensus set out in Table 5.1 is based on consistent and compelling Canadian and international evidence that increased provision of services and supports in the community is highly beneficial for people living with mental illness. It indicates also that relying primarily on services and supports delivered in the community does not cost more than mental health delivery systems that rely predominantly on institutions for the provision of services. A recent paper produced for the World Health Organization (WHO) noted that “community-based mental health services generally cost the same as the hospital-based services they replace.”<sup>148</sup>

**Relying primarily on services and supports delivered in the community does not cost more than mental health delivery systems that rely predominantly on institutions for the provision of services.**

**People living with mental illness can live productive and meaningful lives in the community.**

It is now widely recognized that people living with mental illness can live productive and meaningful lives in the community. That is not to say that people with a serious mental illness will not require intermittent periods of institutional care. Rather, it points to the need for policies to be put in place to make certain that the right conditions are in place to support as many people as possible living in their communities.

As Elliot Goldner pointed out in summarizing the results from a number of mental health studies financed by the Health Transition Fund:

Up until recently, hospitalization for psychosis was seen to be the safest route for the patient and society. It was believed to be too risky to try to treat psychotic patients at home. But Home-Based Program for Treatment of Acute Psychosis in Victoria added further weight to previous studies (e.g., Wasylenki, Gehrs, Goering, & Toner, 1997) that showed these patients can be safely managed, stabilized, and returned to a reasonable level of function without the disruption of admission to a psychiatric unit.<sup>149</sup>

In fact, many people achieve better outcomes when the proper services and supports are provided in the community. A recent report by the Community Mental Health Evaluation Initiative (CMHEI) in Ontario concluded:

<sup>148</sup> Health Evidence Network, World Health Organization. (August 2003) What are the arguments for community-based mental health care? p. 4.

<sup>149</sup> Goldner, E. (2002) Mental health. Health Transition Fund Synthesis Series, Health Canada, p. 8.

**Table 5.1 Excerpts from Provincial Documents**

	<i>Recovery/person-centred</i>	<i>Community-based</i>	<i>Integrated continuum of care</i>
Nfld.	<p>2001<sup>150</sup></p> <p>Person-Centered and Participatory:</p> <ul style="list-style-type: none"> <li>▪ [the system is] responsive to the unique needs of the individual, across all age groups</li> <li>▪ individuals and communities define their own needs and participate in the planning and delivery of services</li> </ul>	<p>Community-Based [system:]</p> <ul style="list-style-type: none"> <li>▪ supports the individual living in the community</li> <li>▪ provides the least restrictive form of care as close to home as possible</li> </ul>	<p>A Comprehensive Continuum:</p> <ul style="list-style-type: none"> <li>▪ provides a continuum of services and supports, including informal supports, focused on well-being and recovery</li> <li>▪ encompasses promotion, prevention, crisis intervention, acute and continuing care, case management and support...</li> </ul>
	<p>2005<sup>151</sup></p> <p>The person/family receiving services must be the central focus of any intervention. Consumer knowledge, expertise and leadership are key components of the mental health and addictions system.</p>	<p>Approaches to be adopted include:</p> <ul style="list-style-type: none"> <li>▪ Establishment of a range of community-based, best practice, specialized mental health/addiction services in each region that best meets the needs of the population.</li> </ul>	<p>The nature of mental illness and addictions often necessitates a comprehensive team approach that involves access to a variety of treatment and support interventions. No one service is usually adequate to meet the diverse needs of this population. Cooperation and collaboration among a range of service providers is essential.</p>
Que.	<p>2005<sup>152</sup></p> <p>Recovery: the action plan reaffirms the ability of individuals to take control of their lives and play an active role in society.</p> <p>Recovery invites us to support individuals with mental illness by helping them resume their role in society, in spite of their symptoms or handicaps, since social interaction is usually how individuals learn that their efforts give them power over their environment.</p>	<p>The mental health network must offer quality services to the entire population (children, youth, adults, cultural communities, Aborigines etc.). To support this vision, the measures in the plan focus on establishing front-line services in local communities, utilizing the expertise of local workers. An organization encouraging a smooth transition to specialized services is the basis for this plan.</p>	<p>Continuity: The action plan focuses on the importance of meeting individuals' needs by breaking down the barriers in our work and providing the necessary liaison to limit interruptions in service.</p>

<sup>150</sup> Government of Newfoundland and Labrador. (September 2001) Valuing mental health: A framework to support the development of a provincial mental health policy for Newfoundland and Labrador.

<sup>151</sup> Government of Newfoundland and Labrador. (2005) Working together for mental health: A provincial policy framework for mental health & addictions services in Newfoundland and Labrador.

<sup>152</sup> Quebec, Ministère de la santé et des services sociaux. (2005) Plan d'action en santé mentale 2005-2010 — La force des liens.

	<i>Recovery/person-centred</i>	<i>Community-based</i>	<i>Integrated continuum of care</i>
Ont.	<p>The consumer is at the centre of the mental health system;</p> <p>1999<sup>153</sup></p>	<p>People with serious mental illness will achieve greater independence; that is, the ability to live in the community with the least intervention from formal services and, to the greatest extent possible, make their own decisions.</p>	<p>Mental health services and supports:</p> <ul style="list-style-type: none"> <li>Are provided within a comprehensive service continuum developed to meet consumer needs and based on best practices.</li> </ul>
	<p>A critical success factor for implementing mental health reform in Ontario is the philosophy that recovery — as defined by the individual, not by service providers — is possible for all people living with mental illness. With the appropriate treatment and supports in place, people living with mental illness can take charge of their lives, create new goals and aspirations, and engage in society as productive citizens.</p> <p>The Provincial Forum believes the recovery philosophy must be embraced and endorsed as an integral tenet of a reformed mental health system.</p> <p>2002<sup>154</sup></p>	<p>A system that creates local systems of care where people living with mental illness, and their families and support networks, can get access to a range of community-based services and supports that are tailored to their needs.</p> <p>Central to the recovery philosophy is the idea that mental health services should be developed within a natural community, not replicated by the mental health system. The community should enable those with mental illness to find gainful employment, participate in supported education programs, and volunteer or participate in society in meaningful ways.</p>	<p>A system that delivers, without fail, a continuum of care — with programs, services and supports available at every stage of life and as close to home as possible.</p>

<sup>153</sup> Government of Ontario. (1999) Making it happen: Operational framework for the delivery of mental health services and supports.  
<sup>154</sup> Government of Ontario. (December 2002) The time is now: Themes and recommendations for mental health reform in Ontario. Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs.

	<i>Recovery/person-centred</i>	<i>Community-based</i>	<i>Integrated continuum of care</i>
Alta. 2004 <sup>155</sup>	Clients and their families will come first. The first and primary purpose of mental health services, plans, research and support is to improve the outcomes for people with mental illnesses and their families. That means services must be appropriate to the circumstances of the people served and that they are treated with dignity and respect. ... And most important, it means people with mental illnesses and addictions are able to live productive and positive lives.	All Albertans should have optimal access to the best mental health care options regardless of where they live in the province. The right services will be delivered to the right clients in the most appropriate setting, whether that's in communities, in community hospitals, or in specialized facilities.	Instead of the fragmented system we see today, mental health services will be fully integrated with the health system and the importance of mental health will be recognized and included in the health care system. Care plans will be in place so people with mental illnesses receive seamless care from multiple service providers and supports provided by a range of health care providers, health authorities, community agencies and provincial ministries.
BC 2004 <sup>156</sup>	The term "client-centred" refers to the unique needs, strengths, motivations and goals of individuals. Client-centred responses "meet people where they are" by removing barriers to access and respecting individual readiness to change. Given the co-morbidity of substance use disorders and mental disorders, client-centred also means providing an integrated and evidence-based system of mental health and addictions care.	Enabling people and groups at the community level to be active participants in, rather than passive targets of, efforts to address problematic substance use is another component of an effective response. Community organizations provide critical support by engaging members of groups most vulnerable to problematic substance use, fostering social inclusion, supporting individuals and families, and by providing a vital bridge for knowledge transfer.	System integration can minimize the fragmentation that allows people to "fall through the cracks". An effective response to concurrent disorders and multiple diagnoses requires a comprehensive, integrated and evidence-based continuum of addictions and health services. These services include health promotion, prevention, harm reduction, early identification, treatment, long-term rehabilitation and relapse prevention, community re-integration and support.

<sup>155</sup> Government of Alberta. (April 2004) Advancing the mental health agenda: A provincial mental health plan for Alberta.

<sup>156</sup> Every Door is the Right Door: A British Columbia Planning Framework to Address Problematic Substance Use and Addiction. BC Ministry of Health, 2004.

Findings from the CMHEI projects clearly show that community mental health is making a difference in the lives of people with serious mental illness, their families, and caregivers. Data indicate that community-based services and supports can help reduce symptoms and increase the ability of people with serious mental illness to live in the community, rather than in hospitals and institutions. Many clients are showing improvement in their daily lives, community functioning, symptoms, and abuse of substances. They also are experiencing fewer crisis episodes and days in hospital.<sup>157</sup>

While the Committee believes that a transformed system must be predominantly based in the community, institutional services also constitute an essential component of the continuum of care. It is the over-reliance on certain kinds of institutional services that has long been the problem. What is required is the right blend of institutional and community-based supports and services. In this regard, the Committee agrees with the approach presented in the paper produced for the WHO cited above:

**While a transformed system must be predominantly based in the community, institutional services also constitute an essential component of the continuum of care. It is the over-reliance on certain kinds of institutional services that has long been the problem.**

In the last two decades, there has been a debate between those who favour providing mental health treatment and care in hospitals, and those who prefer providing it in community settings, primarily or even exclusively. A third alternative is to utilize both community services and hospital care. In this balanced care model, the focus is on providing services in normal community settings close to the population served, while hospital stays are as brief as possible, promptly arranged and used only when necessary. This balanced interpretation of community-based services goes beyond the rhetoric about whether hospital care or community care is better, and instead encourages consideration of what blend of approaches is best suited to a particular area at a particular time.<sup>158</sup>

Many of the services that people need to live successfully in their communities may well emanate from institutions such as hospitals. The key issue is to ensure that those services are accessible in the community and that the people who need them are not admitted unnecessarily as in-patients. Community-based services must be accessible, appropriate, in the right place at the right time, and the least restrictive possible while, of course, achieving good clinical outcomes. Many hospitals run excellent community-based programs that meet these criteria.

**Community-based services must be accessible, appropriate, in the right place at the right time, and the least restrictive possible while, of course, achieving good clinical outcomes. Many hospitals run excellent community-based programs that meet these criteria.**

<sup>157</sup> Community Mental Health Evaluation Initiative (CMHEI). (October 2004) Making a difference: Ontario's community mental health evaluation initiative, p. 43.

<sup>158</sup> Health Evidence Network, World Health Organization. (August 2003) What are the arguments for community-based mental health care? p. 5.

Moreover, it is important to ensure that as many service providers and stakeholders as possible join together in a common purpose. While in-patient resources must be valued and continue to be available, the reform process should result in the reorientation of all services to support community living and the avoidance of hospitalization.

## 5.2 SOME ADVANTAGES OF COMMUNITY-BASED SERVICES

### 5.2.1 Many Community-Based Services can Save Money

As already noted, the evidence suggests that “community-based models of care have been shown to be largely equivalent in cost to the services they replace, so they cannot be considered primarily to be cost-saving or cost-containing measures.”<sup>159</sup> On the other hand, a community-based system need not be more expensive than an institutional one. In fact, there are many specific services and supports that can be provided more cheaply in the community than in hospital.<sup>160</sup>

Consider the following example.<sup>161</sup> Five years ago, a high-support housing program opened its doors to 30 of Ontario’s most severely disabled people. The residents ranged in age from 41 to 69 and had been ill, on average, for 27 years. They all had a serious mental illness as well as other serious medical conditions:

- 9 had diabetes;
- 8 had a history of substance use problems;
- 6 were developmentally delayed;
- 6 had been ordered into treatment by the Ontario Review Board;
- 5 had serious arthritis;
- 3 had chronic obstructive pulmonary disease;
- 3 had seizure disorders;
- 1 had cancer.

Previously, all had been long-term in-patients in provincial psychiatric hospitals; many of them, despite repeated attempts, had been unable to manage in non-hospital, non-institutional accommodation.

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<sup>159</sup> *Ibid.*, p. 15.

<sup>160</sup> Ontario Federation of Community Mental Health and Addiction Programs. (2003) Outcomes and effectiveness: The success of community mental health and addiction programs, pp. 8-9.

<sup>161</sup> Ontario Federation of Community Mental Health and Addiction Programs. (2004) The benefits of funding addiction and mental health services, pp. 7-8.

In the housing unit, the program itself provided the support services that the residents required to cope with their mental illness. Another service provider took care of the residents' medical needs.

Despite the severity of their conditions, these residents have fared remarkably well since entering the program. They have developed a sense of community; they support each other and achieve goals that they could not have previously.

The residents have spent very little time in hospital, saving the health care system an estimated \$4,400,000 annually (or \$146,000 per resident). This estimate was derived from the number of days each resident would have spent in hospital had he or she not moved to the residence, multiplied by the hospital per diem, minus the current cost of the person's residential program.

The cost saving illustrated in this example is by no means unique. In Ontario, for example, the 3,130 clients who received Assertive Community Treatment (ACT) services in 2003-2004 spent 26 days in hospital compared with an average of 77 days in the previous year, a reduction of 87%. In 2003-2004, 66% of ACT clients in Ontario were not admitted to a hospital. It is estimated that ACT achieved a cost avoidance of \$82 million in 2002-2003 and \$77.6 million in 2003-2004.<sup>162</sup>

In addition:

- Steve Lurie, Executive Director, Canadian Mental Health Association (CMHA) Metro Toronto, has demonstrated a decrease in total hospitalization costs from \$1,358,136 to \$172,692 for 56 people receiving comprehensive case management services;
- Wendy Czarny, reports an 89% reduction in the average amount of time residents spend in hospital after enrolling in the supportive housing programs of the Waterloo Regional Homes for Mental Health.<sup>163</sup>

The same types of savings are also achieved in programs that focus on the treatment of substance use disorders based in the community. For example:<sup>164</sup>

- 89% of people with a substance use problem who were treated in a community-based withdrawal management service showed continued positive outcomes six months after treatment in terms of significantly reduced substance use and improvements in self-esteem and self-confidence;
- Without community-based withdrawal management services, 5% of potential clients are likely to be in jail and 11% in hospital;

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<sup>162</sup> Ontario Ministry of Health. 2003/4 ACT data outcome monitoring report.

<sup>163</sup> Examples drawn from: Ontario Federation of Community Mental Health and Addiction Programs. (2003) Outcomes and effectiveness: The success of community mental health and addiction programs, pp. 9 and 12.

<sup>164</sup> *Ibid.*, p. 9.

- Each dollar spent on community-based treatment of alcohol use disorders saves between \$4.00 and \$12.00 in long-term societal, economic and medical costs;
- The scarcity of withdrawal management services in the community forces many people to turn to hospital emergency rooms for service. Indeed, research suggests that, by a very conservative estimate, alcohol-related problems account for between 10% and 30% of all emergency room visits.

### 5.2.2 Other Advantages to Basing Services in the Community

It is clearly easier in a community-based system to incorporate community input and to adapt the system to community needs and values than in a system that is institutionally based. Locating services and supports as much as possible in the community also makes it easier to hold those who are responsible for organizing and delivering them accountable to the community itself.

The Committee believes that these features of community-based systems are of particular importance in ensuring that the care, services and supports that are available to Canada's Aboriginal peoples are fully adapted to their traditions. Moving towards a community-based system thus opens the door for Aboriginal communities to be fully involved in the design and implementation of the mental health programs they require to meet their needs.<sup>165</sup>

**Locating services and supports as much as possible in the community also makes it easier to hold those who are responsible for organizing and delivering them accountable to the community itself.**

**Moving towards a community-based system thus opens the door for Aboriginal communities to be fully involved in the design and implementation of the mental health programs they require to meet their needs.**

Moreover, community-based services offer many additional opportunities to integrate those services and supports in a way that puts the consumer at their centre. It becomes easier to avoid the creation of "silos" by making the delivery of community-based services the focus, regardless of the source of their funding.

Finally, basing services in the community allows volunteers and family members to play a larger role in their organization and delivery; this can both help to expand the range of services and supports that are available to people living with a mental illness, and gear them as much as possible to fostering recovery.

**Basing services in the community allows volunteers and family members to play a larger role in their organization and delivery.**

## 5.3 AN INTEGRATED CONTINUUM OF CARE

Before making specific recommendations on how to put in place an integrated continuum of care that is primarily community-based, it is necessary to look more closely at what such a

<sup>165</sup> See Chapters 13 and 14 for an extensive discussion of issues relating to the mental health and well-being of people of Aboriginal origin in Canada.

system would look like. The final report of the Provincial Forum of Mental Health Implementation Task Force Chairs in Ontario contained a succinct description of the difference an integrated continuum of care would make in the lives of people living with mental illness. It deserves to be cited in full:

### **What will be different**

Individuals with a psychiatric disability live in integrated housing that they have selected in their community; work in jobs and/or participate in meaningful activities that they have chosen; have positive relationships with their families; and have friends who rely on them for support and on whom they can rely.

Individuals have services and supports available that they have had a central role in developing, selecting among, and evaluating. These services and supports are focused on supporting people in their recovery processes in their local communities, and are delivered as close to home as and in the least intrusive way possible.

Individuals have access to a comprehensive, well-integrated and balanced range of community, ambulatory and inpatient services and supports, offered by both professionals and peers.

Services and supports are offered in the context of and are responsive to people's economic, cultural and social situations, are based on the latest relevant knowledge and are oriented toward successful coping, empowerment, self-direction and recovery.

Efforts to change negative public attitudes and their resulting behaviours, such as discrimination, are in place in local communities and are working. Local community resources and the responsibility to include all citizens in community life are seen as an integral part of the community framework for support.

Users of services have the resources and authority to hold service providers and funders accountable for the quality of mental health treatment, services and supports they receive.

Individuals with a psychiatric disability are not defined by their disability or illness, are recognized for their strengths and are empowered and have the resources to define and live the lives they want to lead to the absolute best of their ability.

Source: Government of Ontario. (December 2002) *The time is now: Themes and recommendations for mental health reform in Ontario. Final report of the Provincial Forum of Mental Health Implementation Task Force Chairs.*

The key types of services that are required to make such a system a reality are presented in graphic form in the diagram "The Continuum of Care." This diagram is drawn from one of

the Ontario Mental Health Implementation Task Force reports (Toronto-Peel Implementation Task Force Report).<sup>166</sup>

This framework does not present a definitive listing and categorization of services and supports; those listed are not exhaustive but are illustrative of the services and supports that are needed. Thus the model should be regarded as one useful way of depicting the range and types of services and supports that are required in a transformed mental health system.

**As discussed in Chapter 3, the Committee believes strongly that mental health issues should be approached from a variety of perspectives, only one of which is the “medical” model.**

One advantage to this framework is that it is able to encompass the full range of services and supports, listed under three “levels of need” (first-line, intensive and specialized), with a fourth category that cuts across the three levels. This terminology moves away from commonly used terms that some associate with an overtly medical approach, i.e., primary, secondary and tertiary care. As discussed in Chapter 3, the Committee believes strongly that mental health issues should be approached from a variety of perspectives, only one of which is the “medical” model.

Each level of need is associated with a particular array of services and supports. People will usually receive most of their services from within a particular level, but they are not limited only to the services within that level.

**First-line refers to prevention, assessment and treatment provided by frontline providers.**

a) *First-line*

*First-line* refers to prevention, assessment and treatment provided by frontline providers, including family physician, primary care clinics, and the providers of mental health services, social services, and hospital emergency services. For most people with mental health problems, the first-line level will be their first contact with mental health services, usually through their family physicians or primary health care teams. When someone’s illness is not too serious or of short duration, the provision of first-line services will usually be enough to meet the person’s needs.

**First-line services and supports therefore must be easily accessible to people no matter what their specific needs.**

**First-line services and supports must be well connected not only to each other, but also to more intensive and “cross-level” mental health services and supports that can be called upon as needed.**

First-line services and supports therefore must be easily accessible to people no matter what their specific needs. Providers at this level must be able to respond to a very wide range of needs, and be extremely sensitive to the confusion, fear, and concern of those experiencing symptoms of mental illness, perhaps for the first time.

<sup>166</sup> These reports build on: Government of Ontario. (1999) Making it happen: Operational framework for the delivery of mental health services and supports.

They need also to be culturally sensitive so that they can respond appropriately to the needs of people from a diversity of backgrounds.

First-line services and supports must be well connected not only to each other, but also to more intensive and “cross-level” mental health services and supports that can be called upon as needed. Individuals who are diagnosed with serious and ongoing mental illness will usually be referred by first-line service providers to intensive or specialized services for further assistance.

b) *Intensive*

*Intensive* refers to mental health assessment, treatment and support services that are provided in community or hospital settings for people with serious mental illness. People living with serious mental illness will often require ongoing, long-term support from service providers, but not necessarily daily contact. Intensive services and supports are designed to provide continuous contact and support for people who, without them, would be at risk for repeated or prolonged institutionalization in health care or correctional facilities. The needs of most people living with a serious mental illness should be met by community-based intensive services and supports. People who suffer from acute, severe impairment in personal functioning and are at significant risk, such as someone with a severe post-partum depression, could also require these kinds of intensive services.

**Intensive refers to mental health assessment, treatment and support services that are provided in community or hospital settings for people with serious mental illness.**

**Services at this level address the serious and complex mental disorders most common among the general population.**

Services at this level address the serious and complex mental disorders most common among the general population (including concurrent disorders, eating disorders, first episode schizophrenia, and personality disorders). Service integration can be facilitated through intensive case management. Intensive services and supports must be well connected to first-line and “cross-level” services and supports and must be able to access, and be backed up by, specialized services and supports so that together they can address people’s unique and/or particularly complex needs effectively.

# THE CONTINUUM OF CARE

## First Line Services and Supports

Information and  
Referral

Outreach and  
Engagement

Initial Assessment and  
Care Planning

Crisis  
Response

Hospital Emergency  
Services

Primary  
Care

## Intensive Services and Supports

Intensive  
Case  
Management

Intensive Community  
Treatment and  
Rehabilitation

Intensive Hospital  
Inpatient and Outpatient  
Services

## Specialized Services and Supports

Assertive Community  
Treatment Teams

Specialized Outreach  
Services

Regional Forensic  
Services

Residential  
Treatment

Specialized Inpatient  
Services

Housing and  
Housing Support  
Services

Educational and  
Vocational  
Support Services

Social-  
Recreational  
Support Services

Consumer  
Community  
Development

Family  
Community  
Development

## Cross-Level Services and Supports

c) *Specialized*

*Specialized* refers to highly specialized mental health programs provided in community or hospital settings that focus on serving people whose serious mental illness is characterized by complex and unstable mental disorders. Only

**Specialized refers to highly specialized mental health programs provided in community or hospital settings that focus on serving people whose serious mental illness is characterized by complex and unstable mental disorders.**

those very few people with serious mental illness who require ongoing, daily contact with service providers will need to access such specialized services and supports. As these services are the most specialized, least available and most expensive resources in the mental health system, they must be reserved for those who truly need them and used only when intensive and cross-level services and supports have failed to work for a given individual.

The following are among those whose problems require that they be addressed at this level:

- elderly people suffering from dementia, psychosis and medical illness,
- people who are developmentally disabled with psychiatric disorders and who often display aggressive behaviours,
- people living with schizophrenia who are chronically psychotic, aggressive or suicidal,
- people with complex, treatment-resistant mood disorders.

Specialized services are not synonymous with long-term, institutionalized care. Rather, treatment, rehabilitation and support services can be provided by multi-disciplinary teams that work in ways to enable many people living with these illnesses to continue to live in the community.

**Specialized services are not synonymous with long-term, institutionalized care.**

Individuals who use specialized services and supports will not always need this level of care. The need of individuals for the whole range of services and supports must be monitored and reassessed continuously as they progress through the recovery processes and as their needs change.

d) *Cross-level*

*Cross-level* services and supports is a term used by the Toronto-Peel Implementation Task Force to refer to those services and supports that may be needed regardless of whether someone is being served at

**Cross-level services include housing and housing supports, educational and vocational services and supports, drop-ins and other social/recreational supports, as well as consumer and family peer/self-help supports.**

the first-line, intensive or specialized level of the mental health system. They include housing and housing supports, educational and vocational services and supports, drop-ins and other social/recreational supports, as well as consumer and family peer/self-help supports. Cross-level services and supports are typically — and most effectively and efficiently — delivered in the community, and are amongst those services and supports most often identified by people living with mental illness and their families as being fundamental to the recovery processes.

### 5.3.1 The Continuum is Local and Complex

The preceding section described the types of services and supports that must be in place for people living with mental illness to live meaningful and productive lives in the community. In the real world, however, what is available will depend on many factors that are unique to the history and circumstances of each community; each will have its own particular mix of services and supports. These will vary not only from province to province, but from region to region and municipality to municipality.

This inescapable regional variation was noted in the mental health plan issued recently by the Quebec government:

The situation in each particular region, as well as available expertise and experience, may mean that the continuum of mental health services differs from region to region. Services must be tailored to suit local needs. At the same time, it is necessary to ensure that a continuum of basic services (what we have called “required services”) is in place.<sup>167</sup>

During its cross-country hearings, the Committee was impressed by testimony that described the integrated provision of community-based services and supports in Brandon, Manitoba. Further investigation by Committee researchers, who visited Brandon during the summer of 2005, confirmed the Committee’s initial impression that Brandon stands out as an example of how hard work and careful planning can yield effective results. But, as noted in Chapter 3, the Brandon experience also illustrates also how efforts to provide an integrated continuum of care are both complex and fundamentally local in nature.

The Committee does not believe it wise to attempt to dictate a uniform model that could be implemented somehow across the country. It is not even possible (or desirable) to do this on a province-wide basis because the effectiveness and efficiency with which services are delivered depend critically on a number of local particularities, including the history of local institutions and the number and characteristics

**The Committee does not believe it wise to attempt to dictate a uniform model that could be implemented somehow across the country.**

**...we had to go through a process of shifting the beliefs of patients and staff to one that supported the principle that people could live with mental illness disability in the community...**

**— Albert Hajes**

<sup>167</sup> Quebec, Ministère de la santé et des services sociaux. (2005) Plan d’action en santé mentale 2005-2010 — La force des liens, p. 72.

of the people who live in each community. The Brandon experience illustrates this critical point. While it cannot serve as a template or uniform model, many valuable lessons can be learned from Brandon's success in integrating mental health services, lessons that can be creatively applied throughout the country.

Southwest Manitoba is largely rural farming country, with Brandon, a city of 45,000, as its major urban centre. Health care in Manitoba is managed through Regional Health Authorities (RHAs). The Brandon RHA serves the city and, in addition, provides referral and other services to the surrounding Assiniboine RHA (112,000 square miles, population 80,000) and to four other RHAs in rural areas to the north and east of Brandon.

For most of the 20<sup>th</sup> century, mental health services for Brandon and the western portion of Manitoba were delivered from the Brandon Mental Health Centre (BMHC), a large psychiatric institution dating from the early 1900s. Mental health leaders in Brandon started planning in the 1980s to transfer the centralized services in the BMHC to the community. The number of beds in the aging BMHC buildings started to decrease in the 1980s, and the BMHC was closed in stages between 1994 and 1999.

**Key principles included recruitment and training of proctor paraprofessional staff to provide close and frequent contact with clients to assist with their independent living.**

**— Albert Hajes**

Albert Hajes, Regional Coordinator, Mental Health Program, Brandon Regional Health Authority, described to the Committee how key aspects of this transition were managed.<sup>168</sup> In the first place, attitudes had to change:

*A very important point is that with the closure of BMHC we had to go through a process of shifting the beliefs of patients and staff to one that supported the principle that people could live with mental illness disability in the community and have good quality of life including a greater participation and full citizenship. It required a shift in thinking away from the traditional institutional model not just in terms of the staff and the patients, but also in the general community.*

As well, Mr. Hajes spoke of the need for advance planning:

*A transition of this magnitude was not possible without the development of strong community-based services within the general community to support clients. Considerable work was done prior to the implementation of mental health reform and the transition of services to strengthen the capacity of the service structure and the community to sustain clients.*

Mr. Hajes then described some of the measures that were taken:

*Key principles included recruitment and training of proctor paraprofessional staff to provide close and frequent contact with clients to assist with their independent living. We worked for the establishment of skill development and*

<sup>168</sup> 1 June 2006, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evd-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*capacity building for clients to acquire the abilities to function with relative autonomy. We helped our clients to gain access to resources and have greater participation within the community. We established the full spectrum of services that are needed to support clients in a normalized community setting.*

Brent White, Program Manager, Residential and Support Services in Brandon, elaborated on the proctor program:

*In Brandon, we have developed something we call a "proctor service," which has been likened to home care service, if you will, for mental health clients. Those individuals provide support services to individuals supporting long-term goals. It involves the client in terms of an empowerment process, engaging them in working towards their goals, which might be living goals, educational goals, vocational, or social goals. We have paid a lot of attention to the provision of supportive social programming as well for people.<sup>169</sup>*

The proctor program has since been adopted by other regions of Manitoba. In Brandon, the proctors, who are mostly employed part-time, each help approximately 150 clients. Proctors are drawn in approximately equal proportions from health professional or psychology students, from people trying to enter the job market, and from retired people looking for part time work; approximately one-third of proctors are themselves former or current clients of mental health services.

Mr. Hajes also stressed the importance of broader community involvement:

**We have paid a lot of attention to the provision of supportive social programming as well for people.**

**— Brent White**

**...there was the need for formation of strong partnerships with other health and social service agencies, hospital services, physicians as well as police, school divisions, property owners and housing authorities and others. ...**

**— Albert Hajes**

*Additionally, there was the need for formation of strong partnerships with other health and social service agencies, hospital services, physicians as well as police, school divisions, property owners and housing authorities and others. ... If we were asking community partners to share in responsibility for service to mental health clients, we also needed to provide a backup service to them.*

Finally, Mr. Hajes explained how the lack of doctors in Brandon served as a catalyst for innovation:

*We have a large generic workforce of community mental health workers that have credentials of psychiatric nursing, psychology and social work. The Brandon Mental Health Centre employed a similar staff that did not include many psychiatrists and physicians.*

*In fact, truth be told, we went through a period of very lean years. At one point in time, we actually had one psychiatrist who came from Winnipeg two or three*

<sup>169</sup> 1 June 2006, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evd-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*days a week to sign the documents, and we had a couple of physicians with some mental health experience. That developed the capability and the capacity of the non-medical workforce to be able to respond to the needs. The competencies of our workforce are significantly better, I believe, than what you would see in most other mental health regions.*

Currently, the various programs in Brandon are coordinated by a management team that meets every two weeks. Mental health programs receive approximately 10% of the total funds of the Brandon Regional Health Authority, which has preserved the mental health budget allocation even in years when deficits loomed.

**First contact with the system can be through a readily accessible and visible “store front” location centrally located in downtown Brandon, close to public transportation and other services on which mental health clients depend.**

First contact with the system can be through a readily accessible and visible “store front” location centrally located in downtown Brandon, close to public transportation and other services on which mental health clients depend. This community-based centre also has close working relationships with several allied services and agencies. One of these is the Brandon Friendship Centre, an Aboriginal peoples’ organization to which people can be referred for traditional culturally appropriate treatments, with funding provided through a services contract with the mental health program.

**Intensive Case Managers serve people who are living in the community but need continuing support to manage their daily lives.**

**There are also programs for people at both ends of the age spectrum.**

Intensive Case Managers serve people who are living in the community but need continuing support to manage their daily lives. The Psychosocial Rehab-Residential Services helps them find accommodation in the rental market, where they have access to the proctor service described above. The Westman Crisis Services is a nurse-run, 24/7 telephone response centre that operates a mobile crisis intervention service as well as a crisis stabilization unit that can accommodate up to eight people for approximately five days. Those who need acute in-patient psychiatric care can be referred to the Centre for Adult Psychiatry, a 25-bed acute care psychiatric hospital facility connected to the Brandon Regional Health Centre.

There are also programs for people at both ends of the age spectrum. Mental Health Services for the Elderly serves seniors in their homes, while those elderly clients who need acute in-patient care can be referred to the Centre for Geriatric Psychiatry. The Centre operates a 22-bed acute care psychiatric unit connected to the Brandon Regional Health Centre and manages to return 70% of people who are admitted from their home environments to their homes after discharge. The Brandon Mental Health Program’s Child and Adolescent Treatment Centre (CATC) is located in its own building next to a high school; it also focuses on enabling each young person affected by a mental illness to return to his or her school, family and community.

## 5.4 COMPLETING THE TRANSITION TO COMMUNITY-BASED SERVICES

Although community-based services are being developed in many regions of the country, such as Brandon, the Committee believes that there is still much to be done to allow people living with mental illness to have access to the services and supports they require to live productively in a community setting. Of those who responded to the Committee's second e-consultation, 80% indicated that the services required by people living with mental illness were not available in their communities.<sup>170</sup>

The consequences of not having access to services and supports in the community are that people living with mental illness must rely on institutional services that are generally much more expensive, and often not as beneficial. Nancy Beck, Director, Connections Clubhouse in Halifax, recounted the case of a 72-year-old veteran with schizophrenia:

*[Clyde] requires a couple of hours a week of personal care and a couple of hours to help prepare meals. As a mental health client, he is not able to access home care and against his wishes, the recommendation is that he receives long-term care. We estimate it would cost \$400 a month to honour Clyde's wish and help him remain in an apartment that he has lived in for 15 years.*<sup>171</sup>

Other witnesses stressed the importance of accessible and appropriate housing not only as the necessary foundation for people living with mental illness to remain in the community, but as a cornerstone of reform of the entire mental health system. In the words of Stephen Ayr, Director of Research, Capital District Health Authority in Halifax:

*The next issue is housing. I need not say anything more than if the issue of housing is not addressed, then it is unlikely that any provincial mental health reform will have an impact on the problem.*<sup>172</sup>

**Of those who responded to the Committee's second e-consultation, 80% indicated that the services required by people living with mental illness were not available in their communities. The consequences of not having access to services and supports in the community are that people living with mental illness must rely on institutional services that are generally much more expensive, and often not as beneficial.**

Witnesses told the Committee that the money that had been spent previously on providing institutional care was not always transferred to the community. Jocelyn Greene, Executive Director, Stella Burry Community Services in St. John's, spoke of the impact of funding cuts to health care during the 1990s:

*In particular, in 1995, the cutbacks from the federal government funding resulted in cutbacks in this province in health care and, in particular, the*

<sup>170</sup> Ascentum Incorporated. (2005) Final report on the online consultation by the Standing Senate Committee on Social Affairs, Science and Technology, pp. 28-29.

<sup>171</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>172</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*closure of 97 out of the 127 long-term beds at the Waterford Hospital, which is our provincial psychiatric facility. It is not too strong to say that none of those savings realized from the closure of those beds went back to the community. Wherever they went, they certainly did not come to those of us who work in the community.*<sup>173</sup>

Further evidence of the difficulties confronted by community-based mental health services can be found in a survey of its members conducted by the Ontario Federation of Community Mental Health and Addiction Programs in 2002. It concluded that:

- Since 1992, most of the Federation's 212 member organizations have experienced a net decrease of 20% in provincial funding for core programs, taking into account the increased cost of operations since then.
- Eighty percent of respondents have had to close programs temporarily to cope with fiscal pressures. Twenty-five percent of them have closed programs permanently.
- Almost half of the people who need the services of the Federation's member organizations must wait for 8 weeks or more to access them.
- For a significant number of programs (18%), the waiting time can be a year or longer.<sup>174</sup>

The Committee was told that the Ontario government is currently making significant investments in mental health services in the community, as are most other provinces. Over the past two years in Ontario, core budgets for community mental health programs have been increased for the first time in 12 years. Despite these efforts, it is clear that there is still a long way to go. For example, Carrie Hayward, Director, Mental Health and Addictions Branch, Ontario Ministry of Health and Long-Term Care, told the Committee that:

**The pattern of use of hospital resources by mental health patients, as revealed by a recent Canadian Institute for Health Information (CIHI) report, suggests that there is still considerable scope for shifting treatment to the community.**

*Ontario has 6,750 supportive housing units for people with mental illness or addictions, but the Provincial Forum of Mental Health Implementation Task Forces called for 10,000 more across the province, so continued federal support for affordable and supportive housing is welcomed.*<sup>175</sup>

More generally, the pattern of use of hospital resources by mental health patients, as revealed by a recent Canadian Institute for Health Information (CIHI) report, suggests that there is

<sup>173</sup> 15 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>174</sup> Ontario Federation of Community Mental Health and Addiction Programs. (2003) Outcomes and effectiveness: The success of community mental health and addiction programs, p. 13.

<sup>175</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

still considerable scope for shifting treatment to the community. The report's analysis of inpatient hospitalizations indicates that mental health patients are more likely to be hospitalized for extended periods than any other patient group. According to the report:

While the Mental Health patient group made up the smallest percent of all hospitalizations, at just over 3%, it had the third highest contribution to total number of days (7.4%), and had the highest average length of stay of all patient groups, at 14.0 days, more than double the national average length of stay.<sup>176</sup>

And:

In contrast to all patient groups, only 50% of patients in the Mental Health group stayed in hospital for seven days or less. Nearly one-quarter of Mental Health patients stayed in hospital for 19 days or more; almost three times higher than all patient groups combined (7%).<sup>177</sup>

According to the Organisation for Economic Co-operation and Development (OECD), acute care inpatients are defined as those patients with an average length of stay in hospital of 18 days or less; those required to stay in hospital for longer than 18 days are classified by the OECD as long-term patients. The nearly one-quarter of mental health patients in acute care hospitals who are there for 19 days or longer are, in fact, long-term care patients who are occupying beds in acute care hospitals. While part of the explanation for longer stays in hospital by mental health patients may relate to the nature of their illnesses, it is nonetheless reasonable to assume that many are being kept in expensive acute care hospital beds because there are no alternatives available in the community.

**The nearly one-quarter of mental health patients in acute care hospitals who are there for 19 days or longer are, in fact, long-term care patients who are occupying beds in acute care hospitals.**

**Many are being kept in expensive acute care hospital beds because there are no alternatives available in the community.**

In fact, witnesses told the Committee as much. Roy Muise recounted his experience:

*I remember the time when I was ready to leave hospital and I had nowhere to go because I had no income and I had no money. I spent 13 days in hospital only because I had nowhere to go. It is very difficult, given the gaps in our employment history, first, to get a place to live and, second, to come up with the damage deposit and things like that while we are trying to turn our lives around. So, yes, there needs to be something done in housing, that is for sure.*<sup>178</sup>

<sup>176</sup> CIHI. (30 November 2005) Inpatient hospitalizations and average length of stay: Trends in Canada, 2003—2004 and 2004—2005, p. 10.

<sup>177</sup> *Ibid.*, p. 12.

<sup>178</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

The use of acute care hospital beds to accommodate mental health patients for an extended period for reasons similar to those that kept Roy Muise — completely unnecessarily — in hospital, represents a serious misallocation of scarce and valuable resources; in all probability, the patients' recovery will likely have been substantially delayed to boot! The Committee believes, unfortunately, that this is precisely what is happening right across the country now.

**The use of acute care hospital beds to accommodate mental health patients for an extended period represents a serious misallocation of scarce and valuable resources.**

## 5.5 THE NEED FOR A MENTAL HEALTH TRANSITION FUND

As noted earlier, the evidence suggests that, while the transition to community-based services should not be looked on as a cost-saving measure, it will not cost government any more to fund a predominantly community-based system than it does to run one heavily dependent on the institutional sector. The question then arises as to why governments have not been able to complete the transition to a community-based system, given that it offers so many advantages to people living with mental illness and yet costs no more once the transition is complete. There are a number of reasons to explain the uneven progress that has been made across the country in moving towards an integrated continuum of mental health care based predominantly in the community.

**The savings that will eventually accrue from downsizing the institutional sector do not materialize all at once; they accumulate gradually as institutional services are phased out.**

**The two systems must operate in parallel over a considerable period of time; this too costs money. There is never a guarantee that the money saved by closing a big institution, for example, will find its way back into the mental health sector.**

The most important of these relates to the dynamics of transferring existing financing from the institutional to the community-based sector. A recent article on the restructuring of mental health policy in Ontario noted that:

Closing psychiatric hospitals, however, takes political will and seed money to develop an infrastructure of community services on which such closures rely. A circular argument lies at its core: while the funds needed to develop community services are tied up in hospitals, hospitals cannot close in the absence of community programs. Transitional funds must thus be allocated to develop a community infrastructure.<sup>179</sup>

There are three points to bear in mind in this regard. First, the savings that will eventually accrue from downsizing the institutional sector do not materialize all at once; they accumulate gradually as institutional services are phased out. The practical problem, therefore, is that there are no immediate savings available from within the mental health

<sup>179</sup> Wiktorowicz, M. (2005). Restructuring mental health policy in Ontario: Deconstructing the evolving welfare state. *Canadian Public Administration*, Vol. 48, No. 3, p. 392.

system to finance the creation of new community-based services. Second, because the phasing out of the old system and the introduction of the new one both take time, the two systems must operate in parallel over a considerable period of time; this too costs money. Third, there is never a guarantee that, over the period of time necessary, the money saved by closing a big institution, for example, will find its way back into the mental health sector.

For these three reasons, the Committee believes that a Mental Health Transition Fund (MHTF) must be established. Such a fund would allow the Government of Canada to make money available to the provinces and territories for investment in services and supports that contribute to the transition toward a community-based, integrated continuum of care for Canadians living with a mental illness. This Fund would be a time-limited investment to cover the costs of the transition and to accelerate the process of developing the community-based system.

**The Committee believes that a Mental Health Transition Fund (MHTF) must be established.**

**This Fund would be a time-limited investment to cover the costs of the transition and to accelerate the process of developing the community-based system.**

Once a new “steady state” has been achieved — when the community-based services and supports, integrated along the full continuum of care, are fully in place — the provinces and territories will be able to sustain the new community-based system with the same level of government spending as was devoted to the old system with its heavy reliance on institutional delivery. Thus, any federal funding directed at helping the provinces and territories move in this direction would be a genuine transition fund; it would not constitute an ongoing obligation for the federal government, nor generate increased costs for the provincial and territorial governments.

The Mental Health Transition Fund is unlike many other federal initiatives called “transition funds,” including those such as the Primary Care Transition Fund. Too often, such federal initiatives have resulted in the creation of new programs that must either be supported by new provincial money or disbanded once the federal programs that sparked their creation come to an end. Such initiatives are not truly transitional in that once they are started they place ongoing obligations on provincial and territorial governments to fund them with “new money” on a continuing basis.

**It is a genuine transition fund in that it is designed solely to cover the costs associated with the shift from one way of organizing mental health services to another that will cost the same once the transition is complete and the transformed system is up and running.**

The Committee has been very careful in crafting its recommendations to ensure that this does not happen in the case of the Mental Health Transition Fund. It is a genuine transition fund in that it is designed solely to cover the costs associated with the shift from one way of organizing mental health services to another that will cost the same once the transition is complete and the transformed system is up and running.

**The Transition Fund approach is the most appropriate way for the federal government to invest in what is a provincial responsibility – the delivery of mental health services.**

The Transition Fund approach is the most appropriate way for the federal government to invest in what is a provincial responsibility – the delivery of mental health services. Because

the federal government is not responsible for the delivery of mental health services in the provinces and territories, it cannot determine which specific services and supports are most appropriately funded with federal money. That requires a detailed understanding of what is needed, which can come only from doing the job day in and day out. Therefore, the provinces and territories must decide how to allocate the money to be transferred.

This, of course, is nothing new. It is in line with many recently negotiated health-related agreements between the federal and provincial/territorial governments. In fact, since the creation of the Canada Health and Social Transfer in 1995 the provinces have been masters of how they spend federal transfer payments related to health and social affairs.

The need for flexibility in relation to federal funding to assist with the diverse local needs of mental health service providers was highlighted by Bonnie Arnold from the Canadian Mental Health Association of Prince Edward Island, who used the example of home care:

*However, home care has a very different interpretation from province to province. We believe that it is critical that the federally transferred funds must be sufficiently flexible that they can be used in the most creative and effective ways to best deliver mental health services to P.E.I. and not be tied to one type of service.<sup>180</sup>*

It is legitimate, however, for the federal government to expect some form of accountability for its funding, in keeping with its responsibilities to Canadians to properly manage public funds. In this case, the federal government, and Canadians generally, should be assured that the money is: (a) spent on mental health projects; and (b) used to increase the total amount each jurisdiction spends to enhance mental health and treat mental illness.

**It is legitimate, however, for the federal government to expect some form of accountability for its funding, in keeping with its responsibilities to Canadians to properly manage public funds.**

Moreover, the Committee intends that these funds must not only be incremental to the existing level of provincial or territorial spending. The amount allocated must also take into account the increases in mental health funding that would occur with the overall growth of health care spending in each province and territory. In other words, the new funding must be over and above provincial mental health spending, which should increase at the same rate as the rest of health care spending in the province concerned.

**To be sure new federal money will be used for its intended purposes, it must be “ring-fenced” in some fashion.**

It is important to clarify two points with respect to the Committee’s insistence on the need for new federal money to be used to supplement provincial or territorial spending. First, the Committee does not specify the new or expanded services in which the provinces and territories should invest. It will be up to each province or territory to allocate the new funding to those particular services it needs most, whether to expand or enhance existing services or to create new ones. Second, if individual provinces and territories are able to save

<sup>180</sup> 16 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

money by enhancing productivity, it is entirely up to them to decide how these productivity savings are best spent.

Many believe that to be sure new federal money will be used for its intended purposes, it must be “ring-fenced” in some fashion. As Christine Davis, President, Canadian Federation of Mental Health Nurses, told the Committee:

*When money is given to ministries of health and then to health authorities, health authorities do what is most pressing, and that is to reduce wait lists for hip surgery, knee replacement, cardiac surgery and that kind of thing. If it is not earmarked for mental health, it is not put into mental illness and addictions. Mental illness and addictions are at the bottom of the hierarchy of health care, and people with those problems are seen as less deserving than others. It almost needs to be earmarked for mental health from the get-go.*<sup>181</sup>

Some witnesses were concerned that ring-fencing funding for mental health could set restrictive limits on the total amount of funding that was available. But even these witnesses agreed that, given the pressing needs to accelerate change in the mental health sector, ring-fencing was a good idea.

**This type of ring-fencing was used in the initial phase of implementing the National Mental Health Policy in Australia.**

This is how Dr. John Service, Chair, Canadian Alliance on Mental Illness and Mental Health, expressed it:

*You put it best yesterday, Mr. Chairman, when you said you are between a rock and a hard place with these ringed funds. On the one hand, it can be cherry-picked in tough times. We know that has happened across the country. I have been in the game for 30 years and it has happened many times in my experience. Ringed funds are very vulnerable. They also are in a ghetto by themselves; they accentuate separation. One of the things that ringed funds and targeted funding can do is kick-start change. It can buy change. If it is done right and it is tied into the longer term and structural change that is needed, it can be helpful.*<sup>182</sup>

The Committee noted in its report on “Mental Health Policies and Programs in Selected Countries” that this type of ring-fencing was used in the initial phase of implementing the National Mental Health Policy in Australia.<sup>183</sup> All levels of government in that country made a commitment to some form of budget protection so that new injections of federal funds would not be negated by a concurrent reduction in state and territory funding. Specifically,

<sup>181</sup> 20 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>182</sup> 21 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>183</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 2 — Mental health, mental illness and addiction: Mental health policies and programs in selected countries, p. 8, <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/soci-e/rep-e/report2/repintnov04vol2-e.pdf>.

the agreement between governments to protect mental health resources had two components:

- a commitment to maintaining the level of expenditure on mental health services; and
- a commitment to reinvest any resources released from closure or rationalization of services back into mental health programs.

The Committee was told by Mr. Dermot Casey, Assistant Secretary, Health and Priorities and Suicide Prevention, for the Department of Health and Ageing, Government of Australia, that efforts to protect mental health spending had been successful, to the point that they were no longer needed. He said that:

**The Canadian Mental Health Commission's expertise on mental health policies and best practices and its arm's-length relationship to government make it better placed than Health Canada to oversee the administration of the Transition Fund.**

*In fact, one of fears of the federal government 10 years ago was that if we were to give money for mental health, then the states and territories would simply take it and spend it somewhere else. We had an agreement with them that they would maintain their level of funding if the federal government added to the pie. We actually tracked the dollars and the states and territories had to report to a system of monitoring expenditure. We do not need that system now, 10 years later, because governments, realizing how important this is at a jurisdictional level, would not use the money for something else because it has become such a political issue in the communities.<sup>184</sup>*

Despite these arguments in favour, it does not appear to the Committee that it is possible to develop at this time a system of ring-fencing that would allow for robust accountability down to the local level. In fact, the Committee commissioned research on the viability of ring-fencing funding for mental health at the level of the Regional Health Authority. The study concluded that not only is there a “lack of coordination of mental health information provincially and nationally, there is limited population needs assessment, service profiling or links between health, social services, justice and education along the journey of care.”<sup>185</sup> In short, the health information system available to track spending on health care, including mental health, is inadequate for the purpose.

The Committee believes, nonetheless, that it is possible to establish a set of procedures, overseen by the Canadian Mental Health Commission, that would ensure that Transition Fund money was spent as intended. Disbursement of the fund should be managed by the Canadian Mental Health Commission, the establishment of which was agreed to by all the Ministers of Health (with the exception of Quebec) and officially announced by the federal

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<sup>184</sup> *Ibid.*, pp. 7-8.

<sup>185</sup> Pepler, E. (October 2005) An evaluation of service delivery and financial data within Alberta for the purpose of evaluating ‘ring-fence’ protection of mental health funding, p. 17.

Minister of Health on 24 November 2005.<sup>186</sup> The Commission's expertise on mental health policies and best practices and its arm's-length relationship to government make it better placed than Health Canada to oversee the administration of the Transition Fund.

The Committee believes that priority should be given to initiatives directed at improving the lives of people living with serious mental illnesses, children and adults alike. Those living with these conditions will benefit most from the delivery of a fully integrated continuum of care. But at the same time, this continuum will make a range of services available in the community that will also assist those living with mild to moderate mental illness.

For example, accessible first-line services are needed as the first point of contact both for those with serious illnesses who will need referrals to intensive and specialized services, and for those who can be cared at the first-line level. Similarly, the development of cross-level services will benefit everyone living with a mental illness, although priority access to such services as supportive housing should clearly be given to people coping with serious illnesses.

**The Committee is also particularly concerned that the mental health needs of children be a consistent and strong focus in the development of community-based mental health services and supports.**

The Committee is also particularly concerned that the mental health needs of children be a consistent and strong focus in the development of community-based mental health services and supports. As reviewed in greater detail in the next chapter, the needs of children and youth are too often an afterthought, left to the end even in discussions of how to improve the overall mental health system. The Committee believes strongly that this must be rectified.

The Committee recommends:

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| 9 | <p>That the Government of Canada create a Mental Health Transition Fund to accelerate the transition to a system in which the delivery of mental health services and supports is based predominantly in the community.</p> <p>That this Fund be made available to the provinces and territories on a per capita basis, and that the Fund be administered by the Canadian Mental Health Commission that has been agreed to by all Ministers of Health (with the exception of Quebec).</p> <p>That the provinces and territories be eligible to receive funding from the Mental Health Transition Fund for projects that:</p> |
|---|---|

<sup>186</sup> See Chapter 16, "National Mental Health Initiatives," for a full discussion of the creation and composition of the Canadian Mental Health Commission.

- Would not otherwise have been funded; that is, projects that represent an increase in provincial or territorial spending on mental health services over and above existing spending on services and supports, plus an increment equal to the percentage annual increase in overall spending on health; and that
- Contribute to the transition toward a system in which the delivery of mental health services and supports is based predominantly in the community.

That in allocating the resources from the Mental Health Transition Fund priority should be given to people living with serious and persistent mental illness and that a strong focus should be maintained on meeting the mental health needs of children and youth.

## 5.6 THE COMPONENTS OF THE MENTAL HEALTH TRANSITION FUND

This section discusses some of the key services and supports that would be eligible for funding under the Mental Health Transition Fund (MHTF). The total funding required for these initiatives will be discussed in Chapter 16.

To repeat the Committee's opinion, the MHTF should have two main components: a Mental Health Housing Initiative (MHHI) that will provide federal funds for the development of new affordable and appropriate housing units as well as for rent supplements to allow people living with a mental illness, who could not otherwise afford to do so, to rent accommodation at market rates; and a Basket of Community Services (BCS) that will assist provinces in providing to people living with mental illness a range of services and supports in the community.

### 5.6.1 The Mental Health Housing Initiative (MHHI)

It would be hard to overestimate the importance of adequate housing for people living with mental illness, in particular those whose illnesses are serious. The scale of the problem is indicated by studies showing that somewhere between 30% and 40% of homeless people have mental health problems, and that 20-25% are living with concurrent disorders, that is, with both mental health problems and addictions.

**Somewhere between 30% and 40% of homeless people have mental health problems, and that 20-25% are living with concurrent disorders, that is, with both mental health problems and addictions.**

The Committee heard a consistent story everywhere. Christine Davis, President, Canadian Federation of Mental Health Nurses, put it this way:

*Housing is protection from illness. Housing is protection from the vagaries of mental illness, from the voices, from the fears. The federal government must address the lack of affordable housing.*<sup>187</sup>

Finding suitable housing is an ongoing challenge. Carol Solberg, Executive Director, Schizophrenia Society of Saskatchewan, explained to the Committee that:

*Most people on social assistance live in very small homes, which are not always in safe parts of town; they may be dingy and do not promote good mental health. I believe that if a person with good mental health had to live in some of those situations they probably would become ill or, if nothing else, depressed.*<sup>188</sup>

Jan House told the Committee of her experience trying to find adequate housing for her daughter in Halifax:

*Physical environment is especially important for those with mental illness; however, because they often have little or no income, they are often forced to live in the worst possible neighbourhoods filled with high crime, drugs and violence. In order to ensure she is living in a safe and positive environment, my daughter has been forced to move three times in one year.*<sup>189</sup>

Witnesses noted the impact that reduced federal funding has had on the availability of affordable housing. According to the CMHA, between 1980 and 2000, the number of affordable housing units created by the Government of Canada dropped from 24,000 to 940.<sup>190</sup> Linda Chamberlain, of The Dream Team in Toronto, spoke of the shortage of available housing:

**Between 1980 and 2000, the number of affordable housing units created by the Government of Canada dropped from 24,000 to 940.**

*That is the whole problem. We do not have enough housing. Most times there is a waiting list of 10 years. Sometimes, some of us have taken five years to get in. That is why [we] need more housing. There is just not enough built.*<sup>191</sup>

Bonnie Arnold, of the CMHA in Prince Edward Island, recounted the challenges that confront agencies in the wake of reduced government housing subsidies, as they continue to

<sup>187</sup> 20 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>188</sup> 2 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>189</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>190</sup> Canadian Mental Health Association. (April 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology.

<sup>191</sup> 15 February 2005,

strive to assist people living with mental illness to secure adequate housing and the services they need.

*While I am speaking about housing, another concern that has come up at the working group level is the fact that subsidized housing programs that were once supported by the federal government no longer exist. It is true that new money has been made available to assist in building housing, but it is impossible for agencies to be able to make the rents affordable to the tenants, who are often single with low income...*<sup>192</sup>

The Committee was also presented with evidence that programs designed to provide support to people living with mental illness do in fact accomplish this goal. Darrell Burnham, Executive Director, Coast Foundation Society/Coast Mental Health Foundation, told the Committee:

*We serve well over 2,000 people. I want to highlight two categories of services. One is that we provide an array of supported housing. Indeed, we pioneered supported housing for people with mental illness in 1974 and now serve over 544 people in many different forms of housing throughout the Lower Mainland in decent neighbourhoods in the community. We have found that it is not only a cost-effective means, in that it keeps people healthy and out of hospital, but also they blend well into the communities. They are not places that stand out and cause any concern in the neighbourhoods, so supported housing works.*<sup>193</sup>

Suzanne Crawford, Program Manager, LOFT Community Services in Toronto, elaborated on the strengths of the supportive housing model:

**Programs designed to provide support to people living with mental illness do in fact accomplish this goal.**

*Why does supportive housing work? We think it works because we promote recovery and independence. We have heard this over and over. We focus on safety. We focus on the physical space. We focus on the 24-hour hands-on support.*

*As I said, we need our psychiatrists. We need our clinicians, but you know what? They come into the home. They are there for an hour and they leave. Who is there for the 24 hours a day? It is the supportive housing, and it is the supportive housing in a very psychosocial model. It offers security. It offers peace of mind. It offers flexibility.*<sup>194</sup>

<sup>192</sup> 16 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>193</sup> 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>194</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Phillip Dusfresne of The Dream Team spoke to the Committee from personal experience:

*I used to live on the street and now I am a member of The Dream Team which is a project that was created by the boards for Mental Health Services and Housing Services back in 1999. ...*

*We demonstrate the life-altering benefits of supportive housing by telling our stories to politicians at the various levels of government, social service agencies, service clubs, high school and university students, consumer groups and other institutions. ...*

*People who live in supportive housing live independently. Each of us is assigned a support worker that we could go to whenever we need help. The support workers could help us get on social assistance. They could help us with résumés if we want to go looking for a job. They could help us with doctor and dentist appointments or day-to-day activities if we are not feeling well, but for the most part, we live independently. We do our own cooking, cleaning, grocery shopping and that. Most of us do not have 24-hour support.<sup>195</sup>*

The Committee was also told about a variety of innovative projects that are under way across the country, both in the governmental and the non-governmental sectors. Audrey Bean, Co-President of L'Abri en Ville in Montréal, told the Committee:

**The Committee was convinced by the testimony it heard that there is need for a major federal investment in housing. More housing units are required; more assistance is needed so that people can afford to rent existing apartments at market rates; and more supportive services are needed so that people can live in the community.**

*We work with the psychiatric institutions to identify people who would benefit from our particular kind of living arrangement. We deal with two things that are essential to stability for someone with a mental illness. One is permanent housing, a home, a place where they can invite people to, a place that reinforces a sense of identity, and a place from which they can then re-relate to their families.*

*Then, what we provide is social support, so that we have dinners, people go to one another's houses and we provide that bridge back to the community for a person who has suffered the isolation that those with a mental illness so often suffer.*

*It is a model that is simple and can be done by any community. We are about ... 100 people, with 30 residents, about 60 or 70 volunteers, and a working board of 20 people. We now have a grant. We had one from Human*

<sup>195</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*Resources Development Canada, and now one from the McConnell Foundation, to replicate our model in other communities in Canada.*<sup>196</sup>

And David Nelson, Executive Director, CMHA, Saskatchewan Division, told the Committee of

*...a positive new initiative in this province that is, I believe, groundbreaking. It is the Saskatchewan Rental Housing Supplement. ... It will assist persons with all types of disability to improve their housing situation, and extends well beyond the stereotypical ramp and washroom modifications generally needed by the physically disabled. It will provide resources to those with mental health problems on a continuing basis to assist with renovations such as larger windows, enhanced security, noise control and housing closer to services. ...*

*The supplement is strictly for people who are in the rental market and it will not go to the landlords. It will follow persons when they change homes.*<sup>197</sup>

The Committee was convinced by the testimony it heard that there is need for a major federal investment in housing. Moreover, the testimony points to three interconnected dimensions to be taken into account with respect to this investment: more housing units are required; more assistance is needed so that people can afford to rent existing apartments at market rates; and more supportive services are needed so that people can live in the community. All three dimensions must be addressed.

The investment required in new supportive housing and supportive services for people living with mental illness cuts across areas both of federal and provincial/territorial responsibility. The provision of the necessary supportive services is a provincial responsibility. Thus, the Committee believes that federal support for these services and supports should be channelled through the Transition Fund to be administered by the Canadian Mental Health Commission. The Committee recommends:

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**That services and supports directed at enabling people living with mental illness to be housed in community settings be eligible for funding as part of the Basket of Community Services component of the Mental Health Transition Fund and administered by the Mental Health Commission**

The Committee believes that the first two interconnected dimensions described above (to build new units and to provide rent supplements) should also be channelled through the Transition Fund. However, in managing the housing portion of that Fund, the Canadian Mental Health Commission should make use of existing structures and bodies at the federal

<sup>196</sup> 21 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>197</sup> 2 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/17evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

level that are already responsible for affordable housing initiatives, such as the Canada Mortgage and Housing Corporation.

The Committee notes that, in March 2005, the federal Minister of Labour and Housing announced that rent supplement programs would henceforth be eligible for funding under the existing Affordable Housing Initiative launched to fund the construction of new affordable housing units. The Committee believes that a similar approach should be used with respect to federal financing of housing initiatives for people living with mental illnesses.

The Committee therefore recommends:

11	<p><b>That, as part of the Mental Health Transition Fund, the Government of Canada create a Mental Health Housing Initiative that will provide funds both for the development of new affordable housing units and for rent supplement programs that subsidize people living with mental illness who would otherwise not be able to rent vacant apartments at current market rates.</b></p> <ul style="list-style-type: none"> <li>• <b>That in managing the housing portion of the Mental Health Transition Fund, the Canadian Mental Health Commission should work closely with the Canada Mortgage and Housing Corporation.</b></li> </ul>
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The recommended size of the Mental Health Housing Initiative is discussed in detail in Chapter 16, along with a financial accounting of other recommendations in this report.

### 5.6.2 The Basket of Community Services

In addition to housing, many services and supports are needed in order to enable people living with serious mental illness to live safely in their communities. Those described below have all been demonstrated to improve the lives of people living with mental illness by making it possible for them to live productively in the community. They are within the Basket of Community Services that are widely recognized by governments as being at the core of a community-based mental health system:

- *Assertive Community Treatment* (ACT) teams that provide continuous and comprehensive treatment, rehabilitation and support services to people with serious mental illness who have multiple and complex needs that cannot be met with less intensive levels of support.
- *Crisis Intervention* units that provide accessible and mobile crisis response services and supports, 24 hours a day and 7 days a week, to clients of all ages.

**In addition to housing, many services and supports are needed in order to enable people living with serious mental illness to live safely in their communities.**

- *Intensive Case Management* that enables people to meet their treatment, support and recovery objectives, maintain positive change, and live as independently as possible in the community.

**It is the particular circumstances of each community that should determine the content of the basket of services that will be most effective.**

The Committee is aware that these three by no means constitute all the services that should be eligible for funding under the Mental Health Transition Fund. Many others, such as early psychosis services, services for people with mental illness involved with the justice system, consumer drop-ins, peer support, employment support programs, concurrent disorder programs, services aimed at the mental health needs of refugees and immigrants, could be funded through the Basket of Community Services. But, as we have already noted, it is the particular circumstances of each community that should determine the content of the basket of services that will be most effective. Therefore, the recommendation below is not intended to be prescriptive; it recognizes explicitly the need for local flexibility, subject only to the condition that the services be community-based.

The Committee recommends:

12	<p><b>That a Basket of Community Services that have demonstrated their value in enabling people living with mental illness, in particular those living with serious and persistent illnesses, to live meaningful and productive lives in the community be eligible for funding through the Mental Health Transition Fund.</b></p> <p><b>That this Basket of Community Services include, but not be limited to, such things as Assertive Community Treatment (ACT) Teams, Crisis Intervention Units and Intensive Case Management programs, and that the only condition for establishing the eligibility of a particular service for funding through the Mental Health Transition Fund be that it be based in the community.</b></p>
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The recommended size of the Basket of Community Services is discussed in detail in Chapter 16.

### 5.6.3 Promoting Collaborative Care

Most people who seek professional help for a mental health problem will likely see a physician first, rather than a psychologist, social worker, or other provider. This is due primarily to the relatively larger proportion

**It is important to encourage implementation of collaborative care initiatives in the development of an integrated, community-based continuum of care.**

of physicians practising in the community and the manner in which the health insurance systems operate in the provinces and territories — in general, only the cost of seeing a physician is paid for by public funds, while the services of other mental health professionals, such as psychologists, often require private out-of-pocket payment.

The Committee believes it important to encourage implementation of collaborative care initiatives in the development of an integrated, community-based continuum of care. Collaborative care is the most promising strategy to improve both access to, and the quality of, treatment and services at the first-line level. A recent American study of “Evidence-Based Mental Health Treatments and Services” reported on the success of collaborative care projects:

**Collaborative care seeks to widen “the collaboration to include a wide variety of mental health providers, consumers and family members in the partnerships.”**

For example, the evaluation of one model of collaborative care using non-physician mental health specialists shows that patients with depression treated with the collaborative care model in primary care settings experienced a significantly greater reduction in symptoms over a one-year period than did patients treated with usual primary care.<sup>198</sup>

The idea of collaborative care builds on “shared care” initiatives that were developed to promote greater cooperation between psychiatrists and family physicians. Collaborative care, in the sense intended by the Canadian Collaborative Mental Health Initiative (CCMHI) seeks to widen “the collaboration to include a wide variety of mental health providers, consumers and family members in the partnerships.”<sup>199</sup>

Dr. Nick Kates, Chair of CCMHI, explained to the Committee that

*...there are a number of benefits to this kind of integration. The first is that it can increase access to mental health services for a large number of individuals who otherwise would not reach services. We know that 72 per cent of individuals with a mental health problem receive no mental health care over the course of a year, but 80 per cent of these individuals visit their family physicians.*<sup>200</sup>

Dr. Kates went on to describe the range of services that could be provided in a primary care setting, including:

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<sup>198</sup> Lehman, A., Goldman, H., Dixon, L., and Churchill, R. (June 2004) Evidence-based mental health treatments and services: Examples to inform public policy. Milbank Memorial Fund, p. 14.

<sup>199</sup> Nick Kates. (17 February 2005) Testimony before the Standing Senate Committee on Social Affairs, Science and Technology, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47). The Canadian Collaborative Mental Health Initiative (CCMHI) is a consortium of 12 national organizations representing community services, consumer, family and self-help groups, dieticians, family physicians, nurses, occupational therapists, pharmacists, psychologists, psychiatrists and social workers funded by the Primary Health Care Transition Fund. The CCMHI is completing a series of 12 reports on collaborative mental health care in Canada and abroad; before its funding terminates in March 2006, CCMHI will publish toolkits designed to help patients and their families, health care professionals, and policy makers to understand the issues involved in, and work with, collaborative mental health care.

<sup>200</sup> 17 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*...early detection, health promotion and prevention, consultation, treatment, monitoring, and even some rehabilitation services, but we would stress the need to see mental health and primary care systems as complementary. One will not replace the other.*<sup>201</sup>

Dr. Kates also told the Committee:

*We also see the benefits of pharmacists, dieticians, care navigators, peer support programs, as well as the greater involvement of consumers and family members. We believe in a model of client-centred care. We think that primary care is in a unique position to be able to do this. Our concept of client-centred care includes the development of collaborative care plans, seeing the consumer as an active partner in treatment, the development of peer support mechanisms, and involving consumers in all aspects of planning, delivering and evaluating mental health services in primary care.*<sup>202</sup>

In its published material, the CCMHI further notes that:

Providing mental health services in primary health care settings can be accomplished through various means, for example: providing direct mental health care in primary health care settings, or providing indirect mental health support to primary health care providers in primary health care settings. In the first instance, mental health care is provided by a mental health specialist; in the second, mental health care is delivered by a primary health care provider who is supported by or consults with a mental health specialist.<sup>203</sup>

It further notes that:

Collaborative mental health care takes place in a range of settings including community health centres, the offices of health care providers, an individual's home, schools, correctional facilities, or community locations such as shelters. Settings vary according to the needs and preferences of the individual, and the knowledge, training and skills of the providers. Collaboration may involve joint assessment or care delivery with several providers present with the consumer, families and caregivers, when appropriate, or it may take place through telephone or written communication. In other words,

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<sup>201</sup> 17 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>202</sup> 17 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/07ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>203</sup> Gagné, M. (June 2005) What is collaborative mental health care? An introduction to the collaborative mental health care framework. Report prepared for the Canadian Collaborative Mental Health Initiative, Mississauga, Ontario, p. 4. [www.ccmhi.ca](http://www.ccmhi.ca).

effective collaboration does not require that the health care providers be situated in the same physical location.<sup>204</sup>

Funding for the CCMHI project expires in March 2006. The Committee believes that the work begun by the CCMHI should be pursued in two ways, and therefore recommends:

13 That collaborative care initiatives be eligible for funding through the Mental Health Transition Fund.

That the Knowledge Exchange Centre to be established as part of the Canadian Mental Health Commission (see Chapter 16) actively pursue the promotion of best practices in the development and implementation of collaborative care initiatives.

### 5.6.3.1 Human Resource Issues

In its final report on the acute care, or hospital and doctor, system,<sup>205</sup> the Committee highlighted overall shortages in human resources in the health care system. Anecdotal evidence suggests that these same shortages affect the mental health sector. Throughout the health care system, an aging workforce, along with long lead times for educating and training new providers, mean that existing shortages are likely to get worse over the coming years.

**It is abundantly clear that the kinds of human resource shortages that pervade the health care sector generally also affect the mental health sector.**

The human resource issues raised during the Committee's hearings intersect with the need to foster collaborative care models in mental health. Although there are few hard statistics on human resources in the mental health field, it is abundantly clear that the kinds of human resource shortages that pervade the health care sector generally also affect the mental health sector. Encouraging the development of collaborative care practices that make more efficient and effective use of existing human resources in mental health is one way of addressing this shortage.

**The absence of national human resource planning affects the mental health sector as much as the rest of the health care system.**

Unfortunately, most recent human resource studies do not provide a detailed breakdown of the human

**It is particularly important to increase the numbers of all mental health providers because so many services and supports that are critical to improving the lives of people living with mental illness are provided outside the health care system as such.**

<sup>204</sup> *Ibid.*, p. 3.

<sup>205</sup> Standing Senate Committee on Social Affairs, Science and Technology. (October 2002) *The Health of Canadians — The federal role. Final report. Vol. 6: Recommendations for Reform.*

resource shortages in the mental health sector. A CIHI report on health care providers has noted, however, that psychologists have the highest mean age of the regulated health professions.<sup>206</sup>

Another example is provided by the National Symposium on Gaps in Mental Health Services for Seniors in Long-Term Care (April 2002), in which shortages of professional and non-professional participants were described as one of the most important problems in the provision of mental health services in long-term care.<sup>207</sup>

The absence of national human resource planning affects the mental health sector as much as the rest of the health care system. In its final report in October 2002, the Committee made several recommendations aimed at increasing the number of health care providers across the complete spectrum of health care professions and occupations. Should these recommendations be implemented, the numbers of mental health providers would increase as well.

The Committee wishes to stress that it is particularly important to increase the numbers of all mental health providers because so many services and supports that are critical to improving the lives of people living with mental illness are provided outside the health care system as such. As elsewhere in the health care system, shortages of health care providers is one of the main factors that contribute to unacceptably long wait times for access to mental health services. The Committee notes that the Canadian Psychiatric Association recently issued benchmark wait times for care for a number of psychiatric illnesses, and believes that this represents a further step towards ensuring that people have timely access to the mental health care they require.<sup>208</sup>

Several other human resource issues specific to the mental health field are given prominence by the need to move toward greater use of collaborative care models. The potential for widespread implementation of collaborative mental health initiatives depends to a considerable extent on the broader health care landscape – the creation of multi-disciplinary primary care teams in particular. The slow pace of primary care reform across the country is cause for particular concern.

In practical terms, the difficulties associated with reforming primary care mean that, for many years to come, many solo-practice general practitioners will continue to provide the bulk of the mental health care that their patients receive. It is well known that the fee-for-service model of physician remuneration discourages physicians from spending the extended periods of time that their patients require to help them with their mental health issues. Dr. Richard Goldbloom, Professor of Pediatrics, Dalhousie University, put it this way in his testimony to the Committee:

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<sup>206</sup> Canadian Institute for Health Information. (Nov. 2001) *Canada's Health Care Providers*, p. 39.

<sup>207</sup> The Canadian Academy of Geriatric Psychiatry and Canadian Coalition for Seniors Mental Health. (June 2003) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 8.

<sup>208</sup> Canadian Psychiatric Association. (March 2006) *Wait Time Benchmarks for Patients With Serious Psychiatric Illnesses*.

*I happen to function currently as a consultant. Most of the children I see are referrals from primary care physicians.*

*It did not take me long to learn that the number one reason for referral is that the primary care physician realizes this will take more than 10 minutes.*

*Sir William Osler once said that when doctors speak of matters of principle, they invariably mean money. There is a practical problem in mental health. That is, that people are paid by the number of patients they see. As long as that is the case, you will not see much mental health care in primary care.*<sup>209</sup>

One measure that could help family practitioners who continue to be remunerated by fee-for-service arrangements, but who wish to enhance their capacity to assist patients with mental health issues, was described to the Committee by Mr. Dermot Casey, Assistant Secretary, Health and Priorities and Suicide Prevention, for the Department of Health and Ageing, Government of Australia.

Mr. Casey told the Committee that three years ago the Australian government had introduced a program designed to facilitate the delivery of care to people living with mental illness; it rewards primary care physicians financially for spending more time with people with mental health problems. He explained how this program came about and its main features:

**Three years ago the Australian government had introduced a program designed to facilitate the delivery of care to people living with mental illness; it rewards primary care physicians financially for spending more time with people with mental health problems. Similar initiatives should be encouraged in Canada.**

*We have been told that if you are a GP and someone comes into your consulting room and you think they have a mental health problem, you keep quiet, because if you open the dialogue, you will still be there 20 or 30 minutes later, and of course, fee for service is the treatment model. We have encouraged them by saying that if it will take 20 minutes, we will pay them extra for taking the time. Currently, about 15 per cent of our GP workforce has enrolled in this program. We have about 3,500 GPs who are now enrolled in this program and recognize themselves as people who can offer slightly more and better mental health care. That is a new program.*<sup>210</sup>

The Committee believes similar initiatives should be encouraged in Canada. Provincial and territorial governments should work closely with the medical associations in their jurisdictions to adjust the fee schedules to reward primary care physicians who increase

**The Committee strongly encourages provincial and territorial governments to pursue initiatives designed to remove this financial barrier and facilitate the easy flow of mental health service providers between institutional and community settings.**

<sup>209</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>210</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 2 — Mental health, mental illness and addiction: Mental health policies and programs in selected countries, Chapter 1, p. 14. <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/soci-e/rep-e/report2/repintnov04vol2-e.pdf>.

the time they spend with patients who have mental health problems. Some provinces have already taken measures in this direction. For example, in New Brunswick, fee-for-service physicians can bill for psychotherapy, patient counselling, and family counselling up to 4 hours per day per patient. They can also be reimbursed for time spent case conferencing with allied mental health service providers.

A study of human resource issues by the Canadian Collaborative Mental Health Initiative pointed to another issue the Committee believes must be addressed. The CCMHI report notes that “differences in compensation are especially apparent for providers who shift between institutional and community care practice environments”;<sup>211</sup> those practising in the community setting are paid less. The Committee believes that such inequities are simply wrong and are likely to inhibit the full development of community-based services. The Committee strongly encourages provincial and territorial governments to pursue initiatives designed to remove this financial barrier and facilitate the easy flow of mental health service providers between institutional and community settings.

## **5.7 OTHER INITIATIVES**

### **5.7.1 Support for Family Caregivers**

Family members play an essential, at times lifesaving, role in caring for persons living with mental illness. Almost 60% of families of people living with serious mental illness are estimated to be serving in the capacity of primary caregivers, usually with little guidance, support, relief or respite.<sup>212</sup> These family members often must also contend with the difficulties of navigating through a fragmented mental health system on behalf of their loved ones.

Recognizing their importance and the value of the care they provide, family caregivers were sought out and invited by the Committee to appear at public hearings in every province and territory. We have given “voice” to their concerns in Chapter 2 and have sought to respond to their input. This report addresses two key matters here: income support and respite care services.

#### ***5.7.1.1 Income Support***

The Committee was told that family caregivers are being financially affected in a number of ways. For example, they often have to take time off from their jobs to care for a family member living with mental illness. In this regard, Dr. Kellie LeDrew, Clinical Director of the Newfoundland and Labrador Early Psychosis Program, noted that:

*I think many times we underestimate the burdens that are placed on families. If you want to look at the cost of mental illness, oftentimes we underestimate the indirect cost of mental illness. Many of these mothers — and oftentimes it*

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<sup>211</sup> Bosco, C. (September 2005) Health human resources in collaborative mental health care. Report prepared for the Canadian Collaborative Mental Health Initiative, Mississauga, Ontario, p. 7.

<sup>212</sup> Toronto-Peel Mental Health Implementation Task Force. (December, 2002) *The Time Has Come: Make It Happen*. A mental health action plan for Toronto and Peel, p. xv.

*is the mother — have had to take time off work. I have had to give numerous notes for mothers who had to take time off work to stay home so that the son does not have to go into the hospital. They do not want to leave him because they are afraid something will happen.*<sup>213</sup>

The Committee believes that caregivers should receive some form of financial assistance from government when they have to leave work temporarily to care for a family member who is mentally ill. A number of compelling reasons lead us to this belief:

- *Persons living with mental illness* benefit by receiving long-term help from a familiar source, outside an institutional setting. With this help they may also be spared contact with the criminal justice system or homelessness.
- *Caregivers* benefit by maintaining stable employment over time. They are also better able to maintain a supportive relationship with the affected family member.
- *Employers* benefit from being able to retain valued staff and avoid costs associated with other forms of leave (e.g., sick leave) that may be relied on when leave to care for a family member is unavailable or available only for brief periods of time.
- *Governments* benefit by keeping caregivers in the workforce and persons living with mental illness out of hospitals, long-term care facilities, prisons, and off the streets, all of which will result in cost savings to the public purse.

**Caregivers should receive some form of financial assistance from government when they have to leave work temporarily to care for a family member who is mentally ill.**

The Committee is aware that Compassionate Care Benefits are currently available to eligible Canadians through Employment Insurance (EI). However, these benefits are restricted to persons who have to be absent from work to provide care or support to a gravely ill family member at risk of dying within six months.<sup>214</sup> Recent reports suggest that this program has been seriously under-utilized by its target constituency, in part at least because of the restrictive eligibility criteria that are currently in place.

Given the enormous surplus in the EI account<sup>215</sup> and the recent decision of the Supreme Court of Canada<sup>216</sup> affirming Parliament's constitutional authority to adapt the EI plan to the

<sup>213</sup> 15 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>214</sup> For a more detailed explanation, see Employment Insurance (EI) Compassionate Care Benefits, [http://www.hrsdc.gc.ca/asp/gateway.asp?hr=en/ei/types/compassionate\\_care.shtml&hs=tyt#Who](http://www.hrsdc.gc.ca/asp/gateway.asp?hr=en/ei/types/compassionate_care.shtml&hs=tyt#Who).

<sup>215</sup> In her November 2004 Report, the Auditor General indicated that the accumulated surplus in the EI account had risen to \$46 billion. See: Office of the Auditor General of Canada. (November 2004) Report, Chapter 8. <http://www.oag-bvg.gc.ca/domino/reports.nsf/html/20041108ce.html#ch8hd3b>.

<sup>216</sup> Reference re *Employment Insurance Act* (Can.), ss. 22 and 23, 2005 SCC 56. <http://www.lexum.umontreal.ca/csc-scc/en/rec/html/2005scc056.wpd.html>.

new realities of the workplace, the Committee believes that it is appropriate to make Compassionate Care Benefits more widely available. Therefore, the Committee recommends:

14	<p>That compassionate care benefits be payable up to a maximum of 6 weeks within a two-year period to a person who has to be absent from work to provide care or support to a family member living with mental illness who is considered to be at risk of hospitalization, placement in a long-term care facility, imprisonment, or homelessness, within 6 months.</p> <p>That eligibility for compassionate care benefits be determined on the advice of mental health professionals and that recipients of compassionate care benefits be exempt from the two-week waiting period before EI benefits begin.</p>
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#### 5.7.1.2 Respite Care Services

The responsibility of providing care and support to a family member living with mental illness can place caregivers at risk of burnout. Brenda McPherson, Provincial Coordinator of Psychiatric Patient Advocate Services for New Brunswick, testified that:

**To avoid caregiver burnout, the Committee believes that respite care services available to families must be significantly improved.**

*...many of our caregivers or parents of these [psychiatric] patients are literally burnt[out]. They have been caring for these individuals since the age of 12, 13 or 14. The caregivers have gone through the justice system, they have gone through foster home systems, and so on. By the time their children are 25 and 30...the caregivers are ... burnt[out], and they have access to little or no resources. That is why I think it is important that the federal government play a role, and partner with the provincial government to enhance the services and the resources that the province has.<sup>217</sup>*

To avoid caregiver burnout, the Committee believes that respite care services available to families must be significantly improved. A variety of models were suggested, including:

- having a public health nurse make home visits to the families of persons recently diagnosed with mental illness to offer information and support;<sup>218</sup>
- providing in-home respite care that frees caregivers to go to their own medical or other appointments, attend support groups, or shop for groceries;<sup>219</sup>

<sup>217</sup> 11 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evf-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>218</sup> Doris Ray, 6 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/18eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

- establishing adult daycare services;<sup>220</sup>
- improving institutional respite care by making it available more often and for longer periods.<sup>221</sup>

Given the diverse needs of family caregivers, and recognizing that these needs may shift over time, it seems logical to make a variety of respite care services available. Therefore, the Committee recommends:

15	<p><b>That initiatives designed to make respite care services more widely available to family caregivers, and better adapted to the needs of individual clients as they change over time, be eligible for funding through the Mental Health Transition Fund.</b></p>
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<sup>219</sup> Menna MacIssac, 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>220</sup> Christine Davis, 20 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>221</sup> Penny MacCourt, 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).



## 6.1 INTRODUCTION

*The greatest omission in the work that I see is that it fails to stress the reality that most of the mental health disorders affecting Canadians today begin in childhood and adolescence. Failure to recognize this fact leads us to dealing with a stage-four cancer, often with major secondary effects, instead of a stage-one or stage-two disease. Like obesity, mental health issues, if not addressed early in life, threaten to bankrupt our health care system. —Diane Sacks<sup>222</sup>*

There are a great many children and youth who are living with mental illness. It is conservatively estimated that as many as 15%<sup>223</sup> are affected at any given time, a total of some 1.2 million young Canadians who live with anxiety, attention deficit, depression, addiction, and other disorders.<sup>224</sup> Further, given that families are usually directly involved in the care and support of their younger members, the impact of these high rates of illness is compounded. When a child or young person lives with mental illness or addiction, so too do his or her family caregivers.

**...a total of some 1.2 million young Canadians live with anxiety, attention deficit, depression, addiction, and other disorders.**

Although one might expect that these high rates of prevalence, coupled with the ready supply of advocates (i.e., parents), would have resulted in a well organized, appropriately funded mental health system capable of attending to the needs of children and youth, this is not the case. The Committee learned from those who appeared before it that the system is fragmented and under-funded, that intervention occurs far later than is necessary, that there is a critical shortage of mental health professionals, and that young people and their families are not being involved in workable, long-term solutions to their serious mental health problems.

Children and youth are at a significant disadvantage when compared to other demographic groups affected by mental illness, in that the failings of the mental health system affect them more acutely and severely. The Committee believes it is imperative to move aggressively to tackle key problems now — with other changes to follow.

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<sup>222</sup> 20 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>223</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 5, Section 5.1.2, p. 86.

<sup>224</sup> *Ibid.*, pp. 86-87.

## 6.2 EARLY INTERVENTION

The importance of early intervention cannot be overstated. When symptoms of distress or illness first appear in a child or young person, regardless of age, family caregivers, health professionals and educators should intervene immediately.

**The importance of early intervention cannot be overstated.**

Also, these interventions must be sustained, where necessary, through the transition into school, and thereafter into adulthood. The Committee shares the view of Dr. Ian Manion, a psychologist, who emphasized the importance of reaching children and youth in all stages of their development:

*If you focus solely on one area you create another garrison. You are saying that that is where the funds should be directed, and that means that a generation of middle-year children and youth lose out, or a generation of adolescents loses out. Of course, if you lose a generation of adolescents you are actually losing the next generation of parents, who will parent those zero-to-three-year-old children down the road. Therefore, you need to have a full appreciation of the continuum of care along a developmental continuum.<sup>225</sup>*

Mental illness and addiction do not respect arbitrary cut-off ages. For this reason, the Committee does not support targeting mental health funds for children and youth in a narrow age range. Instead, our focus will be on the establishment of a fully integrated and seamless continuum of services through to and including adulthood.

**...we advocate an end to the practice of terminating mental health or social services when the client has reached a predetermined age (e.g., 16 or 18 years), after which he or she is expected to seek help through the adult system(s).**

Further, we will advocate an end to the practice of terminating mental health or social services — *both* of which are important to good mental health — when the client has reached a predetermined age (e.g., 16 or 18 years), after which he or she is expected to seek help through the adult system(s).

### 6.2.1 The Pre-School Years

While much of the testimony heard by the Committee emphasized the importance of early intervention, most often it was discussed as applicable to school-age children. The logic and convenience of locating mental health interventions within the education system must not blind us, however, to the reality that problems can and do arise prior to enrolment in school. As Sharon Steinhauer, a member of the Alberta Mental Health Board, explained:

*We know that the risk factors come out of the kinds of family and community environments that kids live in.... The question is: Do we have ways of identifying children who are at risk, and do we have ways of capturing them*

<sup>225</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-c/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-c/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*into support networks so that, in fact, we are mitigating some of the risks that may make their family vulnerable?*

*The first place is where kids are raised, of course, and that is families; secondly, is in school. Thus those early years, which the ECD [Early Childhood Development] strategy is trying to address, is the preschool piece. We are trying Head Start programs and a number of other avenues to try to identify those kids who may need more support than is naturally available to them.<sup>226</sup>*

As children mature, they will bring their emerging mental health problems with them into the school environment. Michelle Forge, Superintendent of Student Services at the Bluewater District School Board, noted that:

*When they do, they will be better for having had a teacher who has been able to help them understand what school looks like and how to make those transitions. It also helps the preschool team to navigate the system. We are a system, and we are very different from anybody else. We know it, and we need to provide the navigation tools and people to do that.<sup>227</sup>*

The pre-school years present two challenges. The first is to identify and provide services to those children who are living with, or who are at risk of developing, mental illness. The second is to manage effectively the transition from early childhood (0-5 years) into the school system. The Committee recommends:

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**That school boards mandate the establishment of school-based teams made up of social workers, child/youth workers and teachers to help family caregivers navigate and access the mental health services their children and youth require, and that these teams make use of a variety of treatment techniques and work across disciplines.**

### 6.2.2 The School-Age Years

Many of the Committee's witnesses spoke of the need to ensure that schools are better equipped to handle children's mental health issues than they are now. Dr. Richard Goldbloom, Professor of Pediatrics, went so far as to remark that, "I see the school as the most

**Many of the Committee's witnesses spoke of the need to ensure that schools are better equipped to handle children's mental health issues than they are now.**

<sup>226</sup> 9 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/21eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/21eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>227</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

underdeveloped site for effective health care of any in the country.”<sup>228</sup> He went on to suggest that:

*...we need a major move of mental health services from their present locations in most communities into the schools. The school is children's natural habitat. For six or eight hours a day, it is where they are, it is where their parents often come and it is where you can deal with the problems in collaboration with the teachers.*<sup>229</sup>

Dr. John Service, Chair of the Canadian Alliance on Mental Illness and Mental Health, echoed these comments:

*If we look at just one group, that is young adults, and we ask young adults why they do not access mental health services, they will often tell us it is because they are in large hospitals, because they are in settings that they feel very uncomfortable going to. ... The way we position our services often dictates that they will not use them very effectively. That is a serious issue. ...*

*Another example that I could use from my own experience as a psychologist for 15 years with children, adolescents and families in Nova Scotia, is that we had difficulty getting children and their families to feel comfortable coming to the hospital. We negotiated with the county school board an agreement where we would offer our mental health services in the schools. That was much more effective. People felt much more comfortable coming and we had access to the teachers.*<sup>230</sup>

There was agreement also regarding the importance of teachers having the training necessary to recognize better mental health issues in their students and to help them find effective treatment, rather than, as now, referring students to already overburdened emergency rooms or relegating them to long waiting lists.

**The Committee stresses the importance of teachers having the training necessary to recognize better mental health issues in their students and to help them find effective treatment.**

Dr. Mimi Israël, Psychiatrist-in-Chief at the Douglas Hospital (Montreal), called for investment

**Development of the school as a site for the effective delivery of mental health services is essential.**

<sup>228</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>229</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>230</sup> 21 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

in the training of non-mental health professionals, including teachers. Specifically, she stated that “we should produce a mental health curriculum that would be integrated into the educational programs of teachers, daycare workers and other health professionals.”<sup>231</sup>

Judy Hills, Executive Director of the Canadian Psychiatric Research Foundation, described one such initiative undertaken by her organization in recognition of the fact that “...research shows that the first person youth go to for help is the teacher.”<sup>232</sup> She commented that:

*...teachers were having problems coping with things changing [in the school system] so quickly. They asked if we would put together a guide to help them until they could get help for the children they were working with. They were facing waiting lists for referrals of up to a year and a half for children in their classrooms.*

*The foundation gathered together a group of experts in the field of education. We had principals, teachers, special education people and youth themselves involved in putting together a handbook entitled ‘When Something’s Wrong.’*<sup>233</sup>

Ms. Hills went on to clarify that:

*We know that teachers cannot be diagnosticians, and we do not want them to be that, but we do want them to have some skills in early identification and to understand some of the mood and behaviour disorders that might be caused by mental disorders. With that, they have a basis on which to go forward.*<sup>234</sup>

Development of the school as a site for the effective delivery of mental health services involves several key steps. First, its potential must be recognized. Second, those services must be relocated from other hospital or community-based sites, or established as new services. Third, teachers must be provided with the time and resources to take on this new, more involved role. Therefore, the Committee recommends:

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<sup>231</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>232</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>233</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>234</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

That mental health services for children and youth be provided in the school setting by the school-based mental health teams recommended in previous section 6.2.1.

That teachers be trained so that they can be involved in the early identification of mental illness.

That teachers be given the time and the practical resources and supports necessary to take on this new role.

### 6.2.2.1 Mental Health Screenings

It was suggested to the Committee that another way of involving schools could be through their administration of screening tools for mental illness. This is a matter of some debate. For example, in her testimony to the Committee, Carolyn Mayeur, recounting her daughter's experience, argued in favour of general screening programs:

*I believe there should be regular screening for mental health through all the grades. Danielle had a chemical imbalance that started when she was very young, but there was no screening mechanism. We could have maybe prevented a lot of what happened if we had caught it early.*<sup>235</sup>

Others, including Dr. Diane Sacks, Past President of the Canadian Paediatric Society, favour a more targeted approach:

*It is positive to recognize that services need to be involved in the school system. The next step is to recognize that we are now able to offer available, inexpensive, easy-to-apply and validated tools for identifying many of these disorders in children. These tools need to be utilized [with] a high risk, definable population identified within the school system.*

*What is this population? These are the children who are frequently absent, failing or dropping out. They need to be tagged and automatically screened for mental health disorders. We do not need to wait until they are in prisons to test them and find out, as they did in the U.S., that up to 80 per cent of prison residents have diagnosable conditions.*<sup>236</sup>

<sup>235</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>236</sup> 20 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Dr. Norman Hoffman, Director of the Student Mental Health Service at McGill University, was more cautious. He stated that:

*We see a trend towards wanting to make these fast diagnoses. Screening programs such as depression screening may increase awareness of the problem of depression, but often all it does is support the idea that depression is a singular biological entity. This idea is highly promoted by the pharmaceutical industry, but has no support in the literature.*

*Depressed moods are a complex problem. Twenty years ago, students would come to see us and they would say, "I feel depressed, I feel down." Now they come in and say, "I think I have depression." We say, "What do you mean? How are you feeling? What is going on in your life?" They answer, "No, I have depression." People want fast answers and fast solutions, but they do not work.<sup>237</sup>*

Later, he continued by offering an alternative to general screening programs:

*We need to have school systems where the teacher-to-student ratio is small enough that teachers know their kids. We do not need to do a depression screening in a school if a teacher knows their kids. They will know which kids are troubled.<sup>238</sup>*

The Committee acknowledges the support shown for a variety of approaches to screening programs. While we are very strongly in favour of early diagnosis, we are mindful not only of the criticisms, but also of the roadblocks to implementing screening programs in schools. These fall into two general categories.

**While we are very strongly in favour of early diagnosis, we are mindful of the roadblocks to implementing screening programs in schools.**

#### 6.2.2.1.1 Legal Roadblocks

As discussed in Chapter 4, Section 4, mental health services are primarily a responsibility of the provinces and territories, whose collaboration would therefore be essential to the implementation of any national strategy of mental health screening. In addition, each jurisdiction's laws regarding the provision of health services in a school setting, consent to medical care, privacy of personal information, and admitting a student for treatment for a specific illness would also have to be followed.

The Committee believes that, to screen students for possible mental health concerns, informed consent is necessary, even though, depending on applicable provincial and territorial legislation, a mental health screening may or may not be among the medical services that require consent. Consent should be obtained from the appropriate person, the student in some cases and his or her family caregiver in others.

<sup>237</sup> 21 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>238</sup> 21 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Provincial and territorial legislation varies with respect to the age at which a person is considered capable of consenting to, or refusing, treatment. Legislation notwithstanding, age is not determinative; a minor or person below a statutory age may well be capable of consenting to medical treatment if he or she understands its nature and consequences.

**The Committee believes that, to screen students for possible mental health concerns, informed consent is necessary.**

For consent to be valid it must be both free and fully informed, the latter meaning that the nature, gravity and any risks of the mental health screening must be conveyed to the person to be screened. Understandable answers must also be given to specific questions asked by the person concerned about the procedure or process. A requirement that consent be given without undue influence or coercion may be particularly important when a student who has not yet reached the age of consent is asked to agree to a mental health screening in the presence of school authorities, health professionals and peers.

Mental health screenings in schools would require appropriate measures to be taken to protect the confidentiality of each student's personal information. If a student is competent and capable of providing his or her own consent, it becomes a legal question whether the mental health screening and its results may be disclosed to the student's family caregiver. The law is not consistent across Canada. In any given situation a family caregiver may be precluded from receiving, being entitled to receive, or being required to receive information about the student's health status and care.

Treatment that might follow a mental health screening would also be subject to significant legal implications. The law relating to consent and confidentiality of information would remain applicable, but the legal requirements with respect to treatment would not necessarily be the same as for the initial mental health screening. Because the nature and consequences of mental health treatment are usually more serious than assessment itself, it is possible that a person who is capable of consenting to a screening, and to controlling the disclosure of its results, would not be capable of consenting to follow-up treatment, or of preventing others (his or her family caregiver, for example) from being advised of the treatment options available.

#### **6.2.2.1.2 Practical Roadblocks**

In addition to the inconsistency of the law pertaining to mental health screenings, there is also the question of what school authorities or family caregivers would do with the information the screening might reveal. At present, only a small percentage of people with mental illness or addiction, including children, actually seek help from health professionals.<sup>239</sup> Yet the existing system is already overburdened.

**It seems unlikely that there would be a sufficient number of mental health professionals available in the near term to assist these children and youth. Given this situation, nothing would be accomplished by the screening; indeed, more harm could be done.**

<sup>239</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 8, Section 8.2.6, p. 163.

If mental health screenings were widely administered in schools, one could reasonably expect that significantly more children and youth would be diagnosed as living with mental illness. Carole Tooton, Executive Director of the Nova Scotia Division of the Canadian Mental Health Association, cautioned the Committee that:

*We are somewhat hesitant now to do presentations in the schools. We get many calls especially for grade 11 classes, where part of the curriculum deals with psychology. We worry that after our presentation that the school does not have a system in place to deal with any problems that arise out of the presentation. We need to know that the teachers and guidance councillors have the proper strategy to deal with a student who realizes he or she might have a problem with depression or thoughts of suicide.*

*We are hesitant because we know that a proper follow-up strategy is essential to the success of our program. If the school does not have a strategy, it struggles to find the proper professionals in the system.*<sup>240</sup>

Indeed, even if the suggested strategy is in place, for reasons discussed in Section 6.3 of this chapter it seems unlikely that there would be a sufficient number of mental health professionals available in the near term to assist these children and youth. Given this situation, nothing would be accomplished by the screening; indeed, more harm could be done.

In summary, while the Committee believes that mental health screenings in schools may offer benefits, there are two reasons why a large-scale screening program should not be started at this time. First, existing inconsistencies among provincial and territorial laws render a national initiative unworkable; unfortunately, there appears to be no current appetite for the extensive law reform needed to resolve these inconsistencies on a Canada-wide basis.

Second, while approaches targeted at specific groups of the student population offer somewhat more promise, the existing shortage of health professionals remains a significant impediment.

Perhaps once the mental health system has been reformed, and either its capacity or efficiency or both have been increased, some limited screening programs — carried out within individual jurisdictions — could be considered.

#### **6.2.2.2 Stigma and Discrimination**

The issue of stigma and discrimination arises throughout this report and is examined in greater detail in Chapter 16.<sup>241</sup> Nonetheless, the Committee feels it is necessary to emphasize

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<sup>240</sup> 9 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>241</sup> For a full discussion of stigma and discrimination see also Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 3.

here the importance of implementing early education and awareness about mental illness in schools.

Often, stigma comes from a lack of knowledge. This ignorance is pervasive among all Canadians. The rationale for targeting educational programs at younger people is simple. As Dr. Simon Davidson, Chief of Psychiatry at the Children's Hospital of Eastern Ontario, pointed out, "we have learned that it is relatively simple to destigmatize mental health with youth. I do not think the same is true of adults."<sup>242</sup>

**"We have learned that it is relatively simple to destigmatize mental health with youth. I do not think the same is true of adults." - Dr. Simon Davidson**

**When resources are scarce, it is best to target information at those who are most receptive to it.**

In short, when resources are scarce, it is best to target information at those who are most receptive to it. Therefore, the Committee recommends:

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|----|--|
| 18 | <b>That students be educated in school about mental illness and its prevention, and that the Canadian Mental Health Commission (see Chapter 16) work closely with educators to develop appropriate promotion campaigns in order to reduce stigma and discrimination.</b> |
|----|--|

### 6.2.3 Post-School — Making the Transition to the Adult System

As stated earlier in this chapter, there is no end date for mental illness. The same cannot be said for the mental health and social services available to children and youth. This common problem is one which the Committee believes *must not* be allowed to continue.

#### 6.2.3.1 Mental Health Services

Abrupt termination of essential services has been rightly characterized as akin to falling off a cliff. Yet this is what happens all too often when young people reach a predetermined age, set out in law or policy, at which they become ineligible for "children's" mental health services. One day they are eligible, the next day — their birthday — they are not. As Dr. Ashok Malla, Head of Research at the Douglas Hospital, noted:

**When young people reach a predetermined age, set out in law or policy, at which they become ineligible for "children's" mental health services. One day they are eligible, the next day — their birthday — they are not.**

*...separation of child/adolescent from adult services I think is artificial and it is counterproductive. While resources for this age group [should] be protected at all costs, disorders with onset during adolescence must be treated within a system that is continuous, so that the expertise is available where the person needs care, as opposed to the person going for...X-number of years to this unit*

<sup>242</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*and then being transferred when they turn that magical age of 18 to another set of programs.*<sup>243</sup>

Some of the situations described to the Committee were quite nonsensical. For example, Dr. Linda Bayers, Executive Director of the Self Help Connection, told us that:

*As for this business of 17 and 18, one time they opened up a mental health clinic next to a high school, which was a hop, skip and a jump away but the kids could not access it unless they were 19 years old. What is wrong with this picture? We have to get a lot smarter about helping people in that age group.*<sup>244</sup>

While one might be tempted to just shake one's head at whatever rationale might underlie decisions of this type, the consequences are very real. Phyllis Grant-Parker described her son's experience this way:

*When you are young and you have mental illness, it is like the system expects you to immediately be an independent adult. In Ottawa, where we live, we could not find him the necessary age-appropriate treatment. The Children's Hospital of Eastern Ontario — CHEO — had no program. The Ottawa First Episode Psychosis Clinic at the Ottawa Hospital had a six-month wait. As a result, my son was hospitalized in a tertiary care hospital housed with chronically ill adults and no rehabilitation program. It is a pretty bleak forecast for a teenager and for his family.*<sup>245</sup>

Children and youth require specialized mental health services. But there is no good reason why such services should exist in isolation from the larger mental health system. The current practice of “guarding one's own turf,” a habit that has resulted in individuals and organizations operating alone, in silos, must cease.

**The current practice of “guarding one's own turf,” a habit that has resulted in individuals and organizations operating alone, in silos, must cease.**

It is the responsibility of mental health professionals to work in concert to tear down barriers within and between the adult and children's systems. All treatment services, be they community-, school- or hospital-based, should be fully integrated to ensure children and youth receive age appropriate interventions for as long as they are needed.

Therefore, the Committee recommends:

<sup>243</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>244</sup> 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>245</sup> 16 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/06evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

That provincial and territorial governments work to eliminate any legislative, regulatory or program “silos” that inhibit their ability to deal in an appropriate fashion with the transition from adolescence to adulthood, and that they adopt the following measures:

- Determine age cut-offs for mental health services for children and youth by clinical, rather than budgetary or other bureaucratic, considerations.
- Where age cut-offs are employed, link services for children and youth to adult services to ensure a seamless transition.
- Where age cut-offs are employed, avoid any “gaps” of time where individuals are ineligible for treatment under both the children and youth and the adult systems

### 6.2.3.2 Social Services

While age cut-offs have resulted in certain nonsensical outcomes in the context of mental health services, those in the arena of social services at times defy belief. Reproduced below, in full, is an exchange between Andy Cox, Mental Health Advocate at the IWK Children’s Hospital in Halifax, and the Committee’s Chair. This discussion occurred at the Committee’s public hearings in Halifax. While not involving a person living with a mental illness, it is illustrative of the gaps in services such people face on an ongoing basis:

***Mr. Cox:** For the first part, I will explain by giving an example. We have a young fellow who is 18 on our inpatient unit. He has been there since October [seven months]. He does not have a mental illness, or any mental health issues. Community services would not house this young man. He came to the ER at the IWK, was admitted, and we have been fighting to find him a place to live. We have three or four cases like that on our inpatient list.*

***The Chairman:** Why was he admitted if he did not have a problem?*

***Mr. Cox:** Community Services gave up on him. He is blind.*

***The Chairman:** You gave him a bed in a hospital because the Department of Community Services, to use your words, gave up on him?*

***Mr. Cox:** Yes, and we have been fighting it, appealing it.*

***The Chairman:** He is occupying a hospital bed because there is nowhere else to go and yet he is not sick?*

***Mr. Cox:** No, he is not.*

*The Chairman: He has not committed a crime?*

*Mr. Cox: No, he has not.*

*The Chairman: You understand how, to ordinary people, this sounds absolutely ridiculous, as well as extremely expensive.*

*Mr. Cox: That is not rare.*

*The Chairman: This is not totally unique?*

*Mr. Cox: No, it is not.<sup>246</sup>*

The problem appears to originate in the wording of certain provincial statutes. As Christine Brennan, Supervisor of Youth and Senior Services at the Office of the Ombudsman for Nova Scotia, explained:

**No person living with a mental illness should be left to languish in a legislative void between the children and youth and the adult systems.**

*...you have to understand that under the Children and Family Services Act in our province [Nova Scotia], it says the minister, until the age of 15, shall provide services, and between 16 and 18 the minister may provide services. "Shall" has been legislatively interpreted to be "you have to." We have noticed a service gap for those youth aged 16 to 17 because the act says the minister "may."*

*Generally, a lot of the youth that need those types of services do not follow case plans that are set for them so they are problem youth. It is easier to terminate a care agreement or not provide those services, which is problematic because the youth that need the services are not getting them because of their problem behaviour.<sup>247</sup>*

The Committee is of the view that *both* mental health *and* social services are critical to staying well. While a seamless continuum of either type of service is beneficial to children and youth, tying the two systems together augments their positive effects.

No person living with a mental illness should be left to languish in a legislative void between the children and youth and the adult systems.

Therefore, the Committee recommends:

<sup>246</sup> 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>247</sup> 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evc-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

That provincial and territorial governments coordinate mental health and social services, and pay particular attention in this regard to ensuring that age cut-offs for social services for children and youth be synchronized with those established for mental health services.

### 6.3 SHORTAGE OF CHILD AND ADOLESCENT MENTAL HEALTH PROFESSIONALS

Canadians have grown accustomed to hearing about a shortage of health professionals in this country. Neither the mental health system, nor the sub-system serving children and youth, has escaped these shortfalls.

The Committee was told repeatedly that there is a need for a much greater number of mental health professionals across Canada, particularly those who specialize in treating young people. Dr. Nasreen Roberts, Director of the Adolescent Urgent Consultation and Inpatient Service at Hotel Dieu Hospital in Kingston, provided one example of this in her testimony:

*Providing very quick care, providing an urgent consult service, is important. I have just done a waiting list from across the country for all the 16 medical schools. The waiting list for triage is two weeks to four weeks. The waiting list to see somebody varies between eight weeks to 18 months.*

*There are less than 500 child and adolescent psychiatrists in the country. If you look at only 14 percent of the severely disordered kids in the general population, that translates to 800,000 kids across Canada. That is taking just the severe disorders; I am not including the 22 percent that I [think] should be [treated]. Those are very important numbers.<sup>248</sup>*

Given that only ten fully trained child psychiatrists graduate from medical school each year,<sup>249</sup> the problem Dr. Roberts refers to will likely be with us for some time.

It is not just a question of increasing the number of psychiatric specialists, however. Shortages of other mental health professionals who specialize in treating children and youth, including psychologists, nurses and social workers, must also be addressed. Therefore, the Committee recommends:

<sup>248</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>249</sup> Global Business Roundtable on Addiction and Mental Health. (September 2005) Special Report to the Premiers of Canada: Guidelines for Working Parents to Promote and Protect the Mental Health of Their Children, p. 2. Available at: [www.mentalhealthroundtable.ca](http://www.mentalhealthroundtable.ca).

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- 21 That governments take immediate steps to address the shortage of mental health professionals who specialize in treating children and youth.

### 6.3.1 Transitional Measures

While the Committee agrees that waiting times must be reduced, we realize that increasing capacity within the system, particularly the training capacity for those mental health professionals who specialize in treating young people, will be a very lengthy process.

**It is not just a question of increasing the number of psychiatric specialists, however. Shortages of other mental health professionals who specialize in treating children and youth, including psychologists, nurses and social workers, must also be addressed.**

The Committee believes it important, therefore, to explore remedies that will bring some relief in the near term. We believe that tele-psychiatry, the use of alternative treatment models, and case conferencing, have that potential. These transitional measures will help to bridge the gap during a period of restructuring designed to enhance the ability of the mental health system to assist children and youth.

#### 6.3.1.1 Sharing Existing Resources — Tele-Psychiatry

The Committee has heard testimony regarding the benefits offered by new technologies. One of these — tele-psychiatry — will be examined in detail in Chapter 12. However, the Committee raises the matter here as it has particular application to mental health services for children and youth.

**Tele-psychiatry will permit the sharing of existing resources with under-served regions only if a basic level of mental health service is already available in those communities.**

Shortages of mental health professionals are usually experienced most acutely in rural and remote areas. Those living in communities with limited or no access to mental health services may be forced to travel great distances for treatment. One of the suggestions put to the Committee to deal with the situation in such communities was increased use of tele-psychiatry. Michelle Forge explained that:

*We do not have a children's psychiatrist in our jurisdiction. Quite frankly, the wonderful access that we have had through tele-psychiatry...I believe it is over 200 psychiatric consultations, has allowed us to do things at the community level that we would not have been able to do otherwise. We need that access. We do not necessarily need it all the time, but we need the access and we need a pediatric community that is willing to support it.*<sup>250</sup>

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<sup>250</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

The key here is access to external expertise by *local* health professionals, be they psychologists, nurses, social workers or primary care physicians. Tele-psychiatry will permit the sharing of existing resources with under-serviced regions only if a basic level of mental health service is already available in those communities. Also, local health professionals and their clients must be willing and able to make use of the technology and the advice provided by consultants at a distance.

Therefore, the Committee recommends:

22	<p>That the use of tele-psychiatry be increased in rural and remote areas, to facilitate the sharing of mental health personnel who specialize in treating children and youth with these communities.</p> <p>That tele-psychiatry be employed both for consultations and for the purposes of education and training of health professionals who work in rural and remote areas.</p>
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### 6.3.1.2 Emphasizing Alternative Treatment Models — Group Therapy

A number of experts proposed the use of alternative treatment models, particularly group therapy, as a way to reduce waiting lists. Andy Cox stated that:

*...my top solution is more groups have to be organized. We have youth sitting on a wait list when we can bring them together and start talking earlier about mental illness and, therefore, we will know in what direction to refer these youth.*<sup>251</sup>

His view was echoed by Dr. Richard Goldbloom, who presented a case described by the British Paediatric Association in which group therapy was used with children living with Attention Deficit and Hyperactivity Disorder. According to Dr. Goldbloom:

**The shortage of mental health professionals who specialize in treating children and youth is clearly critical.**

*The waiting list of children referred for assessment of possible attention deficit disorder had tripled over a one-year period. To deal with this, they held patient information sessions targeted at parents who had been on the clinic wait list for nine months or more.*

*They reduced the wait list. Many of these children were put in treatment through group sessions. They reduced the wait list from 20 months to zero over a period of only seven months. It can be done.*<sup>252</sup>

<sup>251</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>252</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

The shortage of mental health professionals who specialize in treating children and youth is clearly critical. However, by educating practitioners in how best to manage waiting lists, particularly through the use of alternative therapies, it may be possible to lessen the impact of the shortage. Therefore, the Committee recommends:

23

That standardized, evidence-based group therapies be used, where clinically appropriate, to reduce wait times for children and youth who need access to mental health services.

### 6.3.1.3 Working Cooperatively — Case Conferencing

As the information in this chapter clearly shows, children and youth are not well served by the mental health system. Hence, all options for improving service levels must be explored, including case conferencing.

Barbara Whitenect, then Acting Director of Child and Youth Services for the New Brunswick Department of Health and Wellness, put it this way:

*One approach we have used in New Brunswick is comprehensive case conferencing. We talk about case conferencing a lot. ... Often, because of demands for service, wait lists or mandates, people do not make the time.*

*We have to look at mandating that and linking it to funding. People have to come together and bring their resources for children, their issues, to the table. ... It is important that we know and understand the dynamics. We will if we are sitting at the same table.<sup>253</sup>*

Ms. Whitenect went on to describe the positive impact flowing from the implementation of the *Youth Criminal Justice Act*:

*When a young person commits an offence, the judge orders the community partners to have a case conference before sentencing. It is too bad that the young person has to commit an offence before we can legislate case conferencing. ...*

*People say, "I have waiting lists," and this and that. If a judge says "You will do it," you do it. We have seen some positive results. It has not overtaxed our people because it is only in those very difficult cases, those high-need situations that we all encounter that we throw our resources onto the table.*

<sup>253</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*I will not overemphasize that, but if we start acting strategically and say our funding dollars are linked to doing these case conferences, thus reshaping the way people do their work, then we can achieve that.*<sup>254</sup>

The Committee believes that case conferencing has the potential to increase the efficiency of the mental health system, while also reducing costs. It is a further example of a transitional measure that may be of some assistance in compensating for the existing shortage of mental health professionals who specialize in treating children and youth. Therefore, we recommend:

**The Committee believes that case conferencing has the potential to increase the efficiency of the mental health system, while also reducing costs.**

24 That provincial and territorial governments encourage their health, education and justice institutions to work closely together in order to provide seamless access to mental health services for children and youth.

That greater use be made of case conferencing so as to coordinate and prioritize mental health service delivery to children and youth.

#### 6.4 INCLUSION OF YOUTH AND FAMILY CAREGIVERS IN TREATMENT

Children and youth pose a particular challenge to mental health professionals. Their bodies and minds are continually growing and changing. Adapting treatment interventions to this reality is a delicate process, one that must be approached with a healthy respect for the client and his/her family caregivers.

Where the family unit is dysfunctional it should be treated as a whole, with all family members provided the assistance they need.

**The Committee believes that it is important to include children and youth and their family caregivers at every stage of the process.**

The Committee believes that it is important to include children and youth and their family caregivers at every stage of the process. Judy Finlay, Chief Advocate for the Ontario Office of Child & Family Services Advocacy, provided the following rationale:

*If we begin to view parents and children as collaborators in assessment, planning, delivery and evaluation of mental health services, it will force a family-based intervention, with the child and the family at the centre. As long as we have a provider-driven system, we will always have the families on the*

<sup>254</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*periphery. We need to move to a family-driven model that enables the child and the family to do well in their community.*<sup>255</sup>

Shifting to this model of service delivery will not be easy. It will require a change in mindset that, to date, has resulted in the mental health system being structured to suit the needs of institutions and providers, not clients. As a first step, it must be recognized that children and youth, and their family caregivers, are full and equal partners — capable of defining the solutions that best meet their own needs. The Committee strongly supports this approach and therefore recommends:

**Shifting to this model of service delivery will not be easy. It will require a change in mindset that, to date, has resulted in the mental health system being structured to suit the needs of institutions and providers, not clients.**

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| 25 | <p>That evidence-based family therapies be employed so that all family members are provided the assistance they need.</p> <p>That professionals interacting with children and youth with mental illness be offered training opportunities to ensure that they can properly address the mental health needs of their younger clients.</p> <p>That family-based treatment of mental illness be integrated into the curriculum of mental health professionals and primary care physicians.</p> <p>That professionals interacting with family caregivers be compensated for this time, in addition to the time spent with the young person living with mental illness.</p> <p>That all practitioners working with children and youth be trained in children's rights.</p> |
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## 6.5 AUTISM

In its first report, the Committee described hearing from mental health professionals who outlined barriers to service delivery, and from family caregivers who spoke of the emotional and financial toll associated with caring for those living with autism. Their statements, in conjunction with a review of the literature, led us then to characterize autism as a “mental disorder.” In retrospect, we should have consulted with persons living with autism before taking this position.

During the public hearings that followed the release of our interim reports on mental health, mental illness and addiction, the Committee again heard testimony on this issue. This time, however, we heard sharply divergent views on what autism is and how the mental health system should respond to it.

<sup>255</sup> 6 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/14ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Norah Whitney, whose child is living with autism, stated that:

*Without effective treatment, autism is a lifelong disorder that results in the placing of over 90 per cent of untreated children in group homes and residential facilities. Only 1 in 64 children will improve without treatment.*<sup>256</sup>

Later she noted that:

*...almost 50 per cent of children with autism who receive treatment before they enter school, ideally at age 2, will go on to become completely indistinguishable from their peers. In other words, with this treatment, there is a 47 per cent recovery rate. Now, I know many people do not believe in recovery when it comes to autism, but I have seen these children with my own eyes, and if I did not know better, I would never be able to detect one trace of autism in their little bodies.*<sup>257</sup>

Ms. Whitney is of the view that autism is an illness<sup>258</sup> that if left untreated will have serious consequences for affected individuals, and their family caregivers. She advocates the early use of Intensive Behavioral Intervention (IBI), describing it as “the only effective treatment that we have for autism.”<sup>259</sup> Also, she points out that family caregivers are experiencing financial hardships associated with the high cost of IBI and the fact that often only limited assistance is available under provincial health plans.

Persons living with autism, such as Michelle Dawson, took strong exception to these arguments. She countered that:

*Autistics have been portrayed by autism advocates in the most dire and horrific terms. We destroy ourselves, our families, and the economy, and there are promises that we will shortly ruin the entire country, so long as we are not expensively fixed. Our continued existence, as ourselves, as autistics, is held to be an affront to the whole idea of Canada.*

*At the same time, autism advocates claim that this impending national catastrophe can be averted if there is unlimited funding for intensive interventions based on applied behaviour analysis, ABA, Lovaas-type or otherwise, for autistics of all ages. ...*

*Autistic abilities and traits are assumed to be non-existent or destructive, useless, and wrong. There is everything to gain and nothing to lose if our lives are dedicated to striving every minute to be normal, that is, non-autistic. The*

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<sup>256</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>257</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>258</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>259</sup> 15 February 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/05eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*goal of this kind of intervention, Ivar Lovaas has repeatedly written, is to build a person where none exists.*<sup>260</sup>

Ms. Dawson is of the view that autism is not a mental illness.<sup>261</sup> She suggests that what is truly needed is “an accurate and unbiased source of information about autism in Canada.”<sup>262</sup> In her view, this report is not the appropriate forum for dealing with this issue.

The Committee recognizes that family caregivers are struggling to provide the best care possible for persons living with autism. Their emotional and financial hardships are very real, and a solution must be found. However, we do not believe that the Committee is well placed to make recommendations at this time. Further study is required if we are to do justice to an extraordinarily complex issue where even the most basic question — “is autism a mental illness?” — remains contentious.<sup>263</sup>

In its earlier report, *The Health of Canadians — The Federal Role*, the Committee laid out the thematic studies to be investigated in future. We are committed to this work, as evidenced by this study of mental health and addiction. In future, we hope to have the opportunity to undertake a thematic study on autism. Meanwhile, we advocate a fuller debate among all stakeholders. In particular, the Committee believes that persons living with autism must be recognized as full and equal partners in the discussion.

## 6.6 CONCLUSION

The Committee is deeply concerned about the capability of the mental health system to respond to the needs of children and youth. Fragmentation, coupled with under-funding, a shortage of mental health professionals, and a failure to involve younger people, and their families in long-term treatment solutions, has resulted in the delayed application of inadequate treatment interventions. Simply put, this is unacceptable. A much greater investment in children’s mental health is required if it is to shed its label as the “orphan’s orphan” within the health care system. By using the Committee’s recommendations as a guide to restructure the system on an urgent basis, it is our belief that an investment in early intervention will result in significant long-term savings within the health care system, and beyond.

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<sup>260</sup> 21 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>261</sup> 21 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>262</sup> 21 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/23eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>263</sup> Both the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association, and the International Classification of Diseases, published by the World Health Organization, classify autism as a mental disorder. However, some experts offer an alternate viewpoint. See, for example, Professor Greg O’Brien’s testimony before the UK Parliament, available on-line at <http://www.publications.parliament.uk/pa/jt200405/jtselect/jtment/79/4102708.htm>], and that of Drs. Betty Jo Freeman and Dr. Ritvo (12 Employee Benefits Cases 1221, 19 A.L.R. 5<sup>th</sup> 1017, 910, F.2d 534 (9<sup>th</sup> Cir.)), available online at <http://www.geocities.com/fishstep/Kunin.html>.



### 7.1 INTRODUCTION

*When we talk about serious and chronic mental illness, we are not [only] talking about Alzheimer's and dementia, which everybody automatically assumes. We are talking about the older adult and senior who have lived their life with schizophrenia, bipolar disorder, or a personality disorder. Because people are aging, obviously we are going to see that more often. These people are probably the most difficult, the most vulnerable and the most forgotten people that we serve. —Suzanne Crawford<sup>264</sup>*

Today, Canadians have a life expectancy of close to 80 years.<sup>265</sup> Increased lifespan, coupled with a declining birth rate, has meant that seniors, aged 65 and over, now represent a large and growing proportion of our population.<sup>266</sup> Of these, 20% are living with mental illness.<sup>267</sup>

**Specialized treatment programs and support services for seniors are lacking, as are the research and knowledge exchange necessary for their development and improvement.**

**Efforts to address deficiencies in existing treatment and support services are consistently hampered by the application of a philosophy of simply “warehousing” those who suffer the disadvantage of being both aged and mentally ill.**

While this rate of incidence is comparable to other age groups, it masks alarming problems such as the 80-90% of nursing home residents who are living with mental illness<sup>268</sup> or some form of cognitive impairment.<sup>269</sup> It also fails to reveal the fact that more elderly seniors are facing particularly acute challenges that include high rates of Alzheimer's disease and related dementias, and for men, a significant incidence of suicide.<sup>270</sup>

<sup>264</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>265</sup> Statistics Canada. *The Daily*, Demographic statistics. (28 September 2005) <http://www.statcan.ca/Daily/English/050928/d050928a.htm>.

<sup>266</sup> By 2016, it is estimated that seniors will represent over 16% of the population, up from 13% today. Penny MacCourt. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 4. By 2026, it is estimated that one in five Canadians will be aged 65 and over, up from one in eight in 2001. Statistics Canada. (2002) *Canada's Aging Population: A report prepared by Health Canada in collaboration with the Interdepartmental Committee on Aging and Seniors Issues*, p. 1.

<sup>267</sup> *Ibid.*

<sup>268</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 5, Section 5.1.3, p. 88.

<sup>269</sup> Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 2.

<sup>270</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 5, Section 5.1.3, p. 88.

In the course of its consultations, the Committee identified a series of significant problems that, while particular to seniors, are simultaneously interwoven within the broader failings of the mental health system. Regrettably, the Committee found that for seniors, as for other population groups, the available treatment and support services are, in general, inadequate. More specifically, specialized treatment programs and support services for seniors are lacking, as are the research and knowledge exchange necessary for their development and improvement.

As well, mental health services are often not available to seniors where they live, an important consideration given the limited mobility of this population. In addition, the fact that seniors often shift from community-based to institutional-based care is often not taken into account and planned for, making the transition both troublesome for the person affected and inefficient. Finally, efforts to address deficiencies in existing treatment and support services are consistently hampered by the application of a philosophy of simply “warehousing” those who suffer the disadvantage of being both aged and mentally ill. Sadly there is little focus on the recovery of seniors affected by mental illness.

## 7.2 SPECIALIZED TREATMENT NEEDS

Seniors are not just older adults whose mental health problems can be addressed within generic treatment programs that are supposedly suited to all ages. They are a demographic segment with unique attributes that distinguish their mental health needs from those of other groups. A participant in the Committee’s on-line consultation described it this way:

**...seniors are a distinct group. They deserve strategies, programs and policies that address their particular issues...  
—Jennifer Barr**

*Seniors with chronic mental health problems are a seriously under-served population. They often do not “fit” mental health services/ residential programs developed for adults (they may have physical/functional/cognitive impairments related to aging in addition to their chronic mental health problems), nor do they necessarily “fit” in long term care programs (they may be very physically and functionally well). —Anonymous*

This perspective was echoed by Jennifer Barr of the Centre for Addiction and Mental Health, who stated that:

*...seniors are a distinct group. They deserve strategies, programs and policies that address their particular issues, as other groups need idiosyncratic programming across the lifespan. We cannot paint everybody with the same brush.<sup>271</sup>*

Also, it is important to recognize that seniors are not a homogeneous group. They encompass a broad range of ages, and their mental health needs vary within these age-groups from youngest to oldest.

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<sup>271</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

The prevalence of Alzheimer's disease serves to illustrate this point. It is widely known that Alzheimer's disproportionately affects seniors. However, while this disease touches 1 in 13 persons over the age of 65, its prevalence increases sharply to 1 in 3 in persons over the age of 85.<sup>272</sup>

Mental health service delivery, and the research that ought to underpin it, must take this diversity into account. As Faith Malach, Executive Director of the Canadian Coalition for Seniors' Mental Health, emphasized in her testimony to the Committee:

*When we talk about "seniors", I am not sure whether there is an assumption that we are talking about a large range of people.... There are vast differences between 65-year-olds and 95-year-olds, and when we are collecting indicators and looking at statistics, we need to remember that even within the seniors' population, there is a huge range.*<sup>273</sup>

The failure of the mental health system to recognize the uniqueness and diversity of seniors' needs may be attributed in part to the lack of knowledge exchange amongst researchers in gerontology, as well as between those who provide care to geriatric populations and the broader community of mental health and addiction care providers. Witnesses went so far as to claim that Canadian researchers working in seniors' mental health "have no idea who each other are," despite their small numbers.<sup>274</sup> The remedy, as Jennifer Barr described it, is that:

*We need to provide gerontology information to mental health and addiction providers. We need to provide mental health and addiction information to gerontology providers. That is putting it very simply. Of course, all this material has to be targeted to the individual setting. Again, it has to be particular to the individuals involved and the particular roles that they play. In terms of knowledge exchange, it has to be complemented by broad public awareness campaigns, and peer and consumer support.*<sup>275</sup>

Having this in mind, the Committee recommends:

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|----|--|
| 26 | <b>That the Knowledge Exchange Centre to be created as part of the Canadian Mental Health Commission (see Chapter 16) have as one of its goals to foster the sharing of information amongst gerontology researchers themselves, and also between providers of specialist care to seniors and other mental health and addiction care providers.</b> |
|----|--|

<sup>272</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental health, mental illness and addiction: Overview of policies and programs in Canada, Chapter 5, Section 5.1.3, p. 88.

<sup>273</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>274</sup> Malach, F. 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-c.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-c.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>275</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

That the Canadian Mental Health Commission encourage research on the broad ranges of ages, environments (i.e., community versus institutional), co-morbidities and cultural issues that have an impact on seniors' mental health, and that it promote best practices in senior-specific mental health programs in order to counter the marginalization of older adults within treatment programs that claim to be suited to all ages.

## 7.3 LOCATION OF SERVICES

### 7.3.1 The Reality: A Provider-Driven Model

The mental health system is provider-driven in that it is generally structured to suit primarily the needs of individual and institutional service providers, not their clients. For example, many mental health services are available only in hospitals or other facilities where health service providers are based. Other characteristics of this provider-centric model were described by Charmaine Spencer, Adjunct Professor of Gerontology at Simon Fraser University, who testified that:

**The seemingly obvious solution to this dilemma is to provide mental health services where older adults live, be it in their homes, the homes of their caregivers, or in acute care or long-term care facilities.**

*...they [seniors] are being limited to things such as a 10-minute visit, or ...one visit, one complaint. They see signs that say that. That is not conducive to good mental health service at any level or to any kind of health service for older adults. For older adults in these circumstances, focusing on one issue at a time leads to a crisis-type of approach....*<sup>276</sup>

The challenge posed to seniors by the provider-driven service model varies, depending on their role as caregivers to another family member, their personal financial resources, and the extent to which their mobility is restricted.

Mobility may be impaired by a variety of factors. Individual seniors may not be comfortable driving or may be incapable of doing so. In many communities, public transportation may be poorly designed or simply unavailable, especially outside of urban centres. Even walking may be impeded by poor sidewalk maintenance, particularly in the winter months. Further, even if transportation is available, seniors often have caregiver responsibilities for a spouse or partner that may hamper their ability to leave the home, and they may lack the necessary funds to make use of respite care or to hire a taxi. In short, the service provider-driven model poses significant structural barriers to the use of services by seniors.

<sup>276</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

### 7.3.2 The Ideal: A Client-Driven Mental Health System

The seemingly obvious solution to this dilemma is to provide mental health services where older adults live, be it in their homes, the homes of their caregivers, or in acute care or long-term care facilities. Jennifer Barr put it this way:

*...similar to your [the Committee's] recommendation around school-based programming for young people where you want to provide programs that are easily accessible, for example, having an addiction counsellor or a mental health support group in a school setting. Similarly, because older adults are, for a number of reasons, not as likely to reach a treatment service, we need to provide the addiction and mental health services where older adults are found, in all that variety of settings.*<sup>277</sup>

It is not sufficient, however, simply to locate mental health services where seniors live. It is necessary as well to provide a full range of services that are suited to the population in question. As Penny MacCourt noted in her brief, submitted on behalf of the British Columbia Psychogeriatric Association:

*For many seniors, the factors that affect their mental health are often related to...deficits in their social support system or environment. Current policy and services...are typically situated within a biopsychosocial model...with an emphasis on the biomedical component. The biomedical model...focuses on individual pathology and leads to the organization of services and programs that focus primarily on the diagnosis and treatment of mental illness. There is a narrow focus on cure and acute care. The biomedical paradigm has led to the neglect of...broader non-medical interventions and community-based services required to support seniors' mental health.*<sup>278</sup>

Thus, services need to be both shifted to the client location and expanded to fit the needs of each particular on-site population. Even once this is done, however, a final step is needed. The gap between the different places in which seniors live must be bridged — that is, the transition of seniors from one location to another over time must be taken into account.

#### 7.3.2.1 Tailoring Services to Where Seniors Live

Life as a senior is often a series of transitions. While some individuals may remain in their homes in comfort until they die, many will shift between their own homes, the homes of family caregivers, acute care and long-term care facilities. The exact details of these transitions are very hard to predict, although we do know that many seniors experience them in some

**The Committee believes that, like those with physical health problems, seniors living with mental illness should be provided treatment and support services in their own homes.**

<sup>277</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>278</sup> MacCourt, P. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 6.

fashion. Seniors may move back and forth between many locations during a period that often extends over three or four decades.

#### 7.3.2.1.1 Seniors Living in Their Own Homes

The Committee believes that, like those with physical health problems, seniors living with mental illness should be provided treatment and support services in their own homes. This should include in-home treatment services by an appropriate mental health service provider and low- or no-cost delivery of medications.

But, as discussed above, the delivery of medical or psychotherapeutic services alone is insufficient. Seniors have additional needs, be they physical (e.g., assistance with the activities of daily living — home maintenance, shopping, cooking, cleaning, or bathing) or social (e.g., visitors or access to library services).

While some recognition has been given to the advantages of maintaining seniors in their own homes, current options are limited. As Terry McCullum, Chief Executive Officer of Leap of Faith, Toronto (LOFT) Community Services, has indicated:

*There are virtually no supportive housing resources if you are an older adult with mental illness and/or addictions.... Your only options are a hospital or a nursing home, but these are expensive, institutional and often not necessary.*<sup>279</sup>

The near-absence of supportive housing resources is not attributable solely to financial constraints. Instead, as Dr. Martha Donnelly, Head of the Division of Community Geriatrics at Vancouver General Hospital, pointed out:

*...most seniors I meet want to stay in their own home, and that is a good place as long as you can get support services in. The problem is there are sometimes policies that do not allow you to bring in the appropriate support services for mental health clients. For instance, in B.C. [British Columbia] right now we can get homemaking help for people who need help to take a bath. However, if people are suspicious and isolating themselves, we cannot get the homemaking services in. Their physical health is considered important, but not their mental health to the same degree.*<sup>280</sup>

This should not be the case. The Committee strongly supports the principle that a full range of treatment and support services should be available for *both* the mentally and the physically ill. We also support the creation of affordable (i.e., subsidized) and supportive housing (i.e., housing options where assistance with the activities of daily living is available on-site). Therefore, the Committee recommends:

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<sup>279</sup> Fine, R. (June 2005) Brief to the Standing Senate Committee on Social Affairs, Science and Technology, Addendum No. 1, p. 1.

<sup>280</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

That money from the Mental Health Transition Fund (see Chapter 16) be made available to the provinces and territories for initiatives designed to facilitate seniors with a mental illness living in the community; these initiatives could include, amongst other things, the provision of:

- home visits by appropriately compensated mental health service providers;
- a range of practical and social support services delivered in their homes to seniors living with mental illness;
- a level of support to seniors living with mental illness that is, at a minimum, equivalent to the level of support available to seniors with physical ailments, regardless of where they reside;
- a more widely available supply of affordable and supportive housing units for seniors living with mental illness.

#### 7.3.2.1.2 Seniors Living With Family Caregivers

The issue of support for family caregivers was examined in Chapter 5. Nonetheless, the Committee believes it necessary to refer here to the particular pressures experienced by those who care for seniors living with mental illness.

**Caregiver responsibilities place seniors themselves at risk for mental illness.**

First, seniors living with mental illness are often cared for by spouses or partners who are themselves seniors. These caregivers may have their own physical or mental limitations, which place an added strain on the relationship and heighten the need of *both* parties for mental health and support services. As Penny MacCourt pointed out in her submission to the Committee, caregiver responsibilities place seniors themselves at risk for mental illness:

*Caregiving women, especially those caring for an individual with dementia...are at increased risk for depression. Caregivers who receive little social support and who feel burdened and/or lonely are more likely to also experience depression than caregivers with good social support.*<sup>281</sup>

Second, seniors living with mental illness often have many concurrent physical and mental incapacities. As a result, they may demand more of their caregivers than a younger family member might. This reality was described by Karen Henderson in her article entitled “The Dichotomies of Caregiving: Mental Health Challenges of Informal Caregivers.” She wrote that:

**Caregivers should not be expected to stand in or substitute for services and supports that should be available to ill family members living alone in their own homes.**

<sup>281</sup> MacCourt, P. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 4.

My caregiving experience taught me that because of the long list of physical and cognitive deficits endured by my father, I ended by adding spouse, parent, personal care aide, friend, chauffeur, decision-maker, advocate, personnel manager, financial manager and funeral planner to my role as daughter. How could anyone fill all these roles and emerge unscathed?<sup>282</sup>

Although not a senior herself, eventually the responsibility of caring for an older adult living with mental illness resulted in Ms. Henderson herself becoming clinically depressed.

In addition to recognizing the value of family caregivers and assisting them in that role, steps must be taken to minimize the risk of their developing mental illness. In particular, caregivers should not be expected to stand in or substitute for services and supports that should be available to ill family members living alone in their own homes. Therefore, the Committee recommends:

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**That seniors with a mental illness who are living with family caregivers be eligible for all of the health and support services that would be available to them if they lived alone in their own home.**

#### **7.3.2.1.3 Seniors Living in Acute Care and Long Term Care Facilities**

Under the service provider-driven model, one might expect seniors to receive appropriate mental health services in the acute care hospitals in which most service providers are based. However, all too often they do not.

One reason for this is the widespread perception in acute care facilities that older adults suffering from mental illness should be accommodated in long-term care facilities and thus “spare” the hospital’s limited resources for higher-priority patients.

**Many older adults are being inappropriately “housed” in acute care facilities. The solution lies in making alternatives to hospitalization more widely available.**

Dr. Elizabeth Drance, a geriatric psychiatrist, addressed this perception and the consequences for seniors, in her submission to the Committee:

*...our frail elders are still considered “bed blockers” and “placement problems” by our acute care environments due to the stresses within the system for beds. The importance of elective admission for geriatric medical and psychiatric assessments, thereby avoiding emergency room admissions, is not well understood by our acute care system caregivers.*

<sup>282</sup> Henderson, K. (October 2002) The Dichotomies of Caregiving: Mental Health Challenges of Informal Caregivers. In Writings in Gerontology: Mental Health and Aging (National Advisory Council on Aging), No. 18, p. 44.

*Many feel that these frail elders do not require admission to hospital at all, and that these beds should be purely utilized only to decant [transfer] patients out of overcrowded emergency rooms. The stress on the acute care system pushes us further away from creating elder-friendly acute care environments, adding to the stress of hospitalization for our frail older adults [and] worsening their mental health.*<sup>283</sup>

The Committee believes that all Canadians should have access to the acute care system, when and where they need it. There are circumstances where seniors living with mental illness require hospitalization, and this service should be readily available to them. We also recognize, however, that many older adults are being inappropriately “housed” in acute care facilities. The solution lies in making alternatives to hospitalization more widely available.

**Today 75 per cent to 85 per cent of the population of personal care homes are persons with cognitive disorders or mental health disorders.**

**—Annette Osted**

**...The consequences of this change have not been adequately addressed.**

When seniors can no longer be maintained in their own homes or with family caregivers, long term care facilities are often a next step. As Dr. Drance has indicated, however, the need of residents for what she terms “care homes” differs from past years:

*...I have seen the population of elders within complex care environments [care homes]...change dramatically over the past 15 years. As more elders stay in their own homes or live in supportive alternatives such as “Assisted Living” environments, the people we are caring for in our care home environments come to us for the following...reasons:*

- *Cognitive impairment/Dementia ...*
- *Severe complex physical illnesses with mobility challenges*
- *End of life care*
- *Mixtures of all of the above*<sup>284</sup>

Her views were echoed by Annette Osted, Executive Director of the College of Registered Psychiatric Nurses of Manitoba, who testified that:

*The changes in population in personal care homes must be met with changes to what services are delivered and how. Thirty years ago the population of personal care homes were the physically frail and elderly. Today 75 per cent to 85 per cent of the population of personal care homes are persons with cognitive disorders or mental health disorders.*<sup>285</sup>

<sup>283</sup> Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 1.

<sup>284</sup> *Ibid.*, p. 2.

<sup>285</sup> 31 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

The consequences of this change have not been adequately addressed. There has been an insufficient increase in staffing levels,<sup>286</sup> not enough support for upgrading caregiver skill levels,<sup>287</sup> and too little enhancement of on-site mental health and support services to meet the increased intensity and modification of care requirements that has been the result of this shift. The end result may be overmedication,<sup>288</sup> the use of chemical restraint,<sup>289</sup> provision of only the most basic or custodial needs<sup>290</sup> — or in short, “warehousing” of our society’s most vulnerable senior citizens.

There are alternatives. Mental health services can be devolved from acute care to long-term care facilities. Support services can be adapted to reflect the shift from physically to mentally frail clients. Committee members who have had a family member living in a long-term care facility described their own experiences with enclosed garden areas employed as an alternative to restraints for persons living with dementia. Attached to long-term care facilities, such areas enable clients to wander freely but safely.

Menna MacIssac, Director of Programs and Operations for the Nova Scotia Alzheimer Society, confirmed that best practices for construction of long-term care facilities have already been established. She pointed to these as “...an opportunity to change the physical and pharmacological environment in which people with dementia are currently living.”<sup>291</sup>

Therefore, the Committee recommends:

29	<p><b>That efforts be made to shift seniors with a mental illness from acute care to long-term care facilities, or other appropriate housing, where it is clinically appropriate to do so, by making alternatives to hospitalization more widely available.</b></p> <p><b>That staffing competencies in long term care facilities be reviewed and adjusted, through the introduction of appropriate training programs, to ensure that the devolution of responsibility for patients living with a mental illness from acute care facilities to long-term care facilities is done in a way that ensures that clinically appropriate mental health services are available to residents on-site.</b></p>
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<sup>286</sup> 31 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>287</sup> Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, pp. 2-3.

<sup>288</sup> MacIssac, M. 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>289</sup> Osted, A. 31 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>290</sup> Drance, E. (June 2005) Brief submitted to the Standing Senate Committee on Social Affairs, Science and Technology, p. 3.

<sup>291</sup> 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

### 7.3.2.2 Managing the Transition

While it cannot be predicted when people will make the shift from own home, to caregiver home, to hospital, to long-term care facility, what can be affirmed, sadly, is that the transition between these locations will not be seamless. Too often it will be inefficient and inconvenient, at worst it may be unsafe. Dr. Drance described the current situation as follows:

**While it cannot be predicted when people will make the shift from own home, to caregiver home, to hospital, to long-term care facility, what can be affirmed, sadly, is that the transition between these locations will not be seamless.**

*There are many services out there, but right now for a frail senior or their loved one to figure out who to call, where to call, that navigator role is a key one. Family physicians need to be able to navigate the system as well. We have not done a good job of gathering all these services together and helping people access them relatively straightforwardly. It is an incredibly complex system.*<sup>292</sup>

There are a number of potential solutions to this problem. First, resources can be invested to help seniors and their family caregivers better navigate the existing system through the use, for example, of professional system navigators. Second, there can be greater centralization of transitional services in traditional locations, i.e., where service providers are currently based (pending implementation of the reforms recommended above). Third, services can be shifted to centralized locations, such as long-term care facilities, where many seniors live.

The Committee believes that the last option would provide the most benefit. However, we suggest that it be taken one step further. In addition to centralizing services in locations where many seniors live, we are of the view that different “homes” for seniors should be put in close proximity to one another, perhaps even under one roof. Menna MacIssac described one such alternative:

*There are facilities now, and we have one here in Capital [Capital Health — Halifax, Nova Scotia] called Northwood, which have an array of services and housing options under the same facility so that as people's needs change — and I am not talking about necessarily dementia, but about a person who has care needs — they can progress through different options. That should be looked to as well.*<sup>293</sup>

This model has the advantage of addressing simultaneously problems associated with mobility and with making the transition from one housing setting to another. It also would accommodate situations in which aged couples with different care needs can continue to live in the different settings most appropriate to their needs but still be in close proximity to one another.

<sup>292</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>293</sup> 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Therefore the Committee recommends:

30 That a range of institutionally based services for seniors living with a mental illness be integrated (e.g., supportive housing units and long-term care facilities) by locating them adjacent to each other, to make the transition(s) between different institutional settings efficient and safe.

That every effort be made to facilitate aged couples being able to continue to live together, or in close proximity to one another, regardless of the level of services and supports that they each may require.

#### 7.4 THE DOUBLE-WHAMMY OF MENTAL ILLNESS AND AGING

The Committee heard that mental health and support services for seniors are falling short of meeting real needs. The question is why? Having reviewed all of the evidence, we concluded that Robena Sirett, Manager of Older Persons Adult Mental Health Services for the Vancouver Coastal Health Association, was right when she stated that:

**I would like us to look at is strategies for eliminating the stigma of the double-whammy of...mental illness and aging. Both are very powerful stigmas, and together they influence the care that people seek and receive.**

—Robena Sirett

*A second...area that I would like us to look at is strategies for eliminating the stigma of the double-whammy of...mental illness and aging. Both are very powerful stigmas, and together they influence the care that people seek and receive.*<sup>294</sup>

Stigma can be subtle, as in the tendency to consider young adults as the norm for all age groups,<sup>295</sup> thereby justifying the exclusion of seniors from mental health guidelines<sup>296</sup> and negating the need for specialized treatment programs. It can also be more overt, as in the tendency to locate mental health and support services in locations that are inaccessible to those with physical or mental incapacities.

Stigma finds expression in the sense of fatalism that too often infects society's attitude toward seniors. Their symptoms of distress are often dismissed as attributable to "just getting old" or "indulging in a last pleasure." Too often seniors are considered a burden, a drain on scarce resources better invested in younger people with greater potential.

<sup>294</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>295</sup> Spencer, C. 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>296</sup> MacCourt, P. 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Stigma is also reflected in the conditions in which many older adults living with mental illness are expected to exist, where hope of recovery is abandoned to overmedication, restraint, and provision of only the most basic custodial needs. The “warehousing” of many, many seniors, as cheaply as possible, is perhaps the ugliest expression of an attitude that does not acknowledge the worth of older people living with mental illness.

As described elsewhere in this report, one of the primary mandates of the proposed Canadian Mental Health Commission will be to launch an aggressive ten-year anti-stigma campaign. A critical objective of that campaign must be to change public attitudes toward seniors who are living with mental illness.

## 7.5 CONCLUSION

A number of the Committee’s members are themselves older adults. It is our hope that by drawing attention to the shortcomings in the mental health system that affect seniors, and providing recommendations for change and improvement, our own futures, and those of our children and grandchildren, will be more secure. In moving forward, we draw inspiration from seniors themselves who, to quote Charmaine Spencer, have pointed out that:

*...in their lifetime they have seen other matters that were previously stigmatized, hidden and never talked about, such as cancer, divorce, pregnancy, and developmental disabilities, become normalized through information, education, and social change. They ask why that is not possible here too.*<sup>297</sup>

The Committee hopes that the work of the Canadian Mental Health Commission will help to make that “normalization” possible as well.

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<sup>297</sup> 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).



## CHAPTER 8: WORKPLACE AND EMPLOYMENT

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It is in the workplace that the human and the economic dimensions of mental health and mental illness come together most evidently. On the one hand, the workplace can contribute positively to mental well-being — it is where we derive a good part of our sense of social integration. As Merv Gilbert, a psychologist at the Mental Health Evaluation and Community Consultation Unit, Department of Psychiatry, University of British Columbia, told the Committee:

**Work has also been found to play an important role in recovery from mental illness.**

*Work provides a sense of structure, social meaning, social supports, a place to go outside the home...and it also provides an income, which we do know is good for your mental health.*<sup>298</sup>

Work has also been found to play an important role in recovery from mental illness. Employment decreases the rate and duration of hospitalization and enhances quality of life. Surveys show that most persons living with serious mental illness want to work and see employment as a primary goal.

**Unemployment for persons living with serious mental illness is estimated to be as high as 90%.**

But few are employed. In fact, unemployment for persons living with serious mental illness is estimated to be as high as 90%.<sup>299</sup> In addition to unemployment, exclusion from the workforce often results in dependency on income security programs for survival. Unemployment leads to impoverishment and reduced social engagement, which in turn may worsen mental and physical illnesses. It also contributes to feelings of worthlessness and depression, and can lead to substance abuse.

While participation in the workforce can contribute positively to mental health it can also contribute to the development of mental health problems, including stress, depression and anxiety. Mr. Gilbert added that:

*Therein we have one of the fundamental paradoxes we face today: Work is good for your mental health and work can make you crazy.*<sup>300</sup>

The issues surrounding mental health and the workplace are complex and multifaceted. As professor Romaine Malenfant from the Université du Québec en Outaouais told the Committee:

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<sup>298</sup> 5 July 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>299</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.1, p. 107.

<sup>300</sup> 5 July 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

*Research increasingly shows that we must not only counter the lack of work, or unemployment, in preserving mental health, but also preserve the quality of work so that work plays its full role in building identity and enabling people to achieve their full potential.*<sup>301</sup>

## 8.1 UNDERSTANDING THE HUMAN COSTS OF MENTAL ILLNESS IN THE WORKPLACE

### 8.1.1 The Many Factors That Contribute to the Development of Mental Illness

Exploring the complex relationship between work and mental health, professor Marc Corbière, from the Institute of Health Promotion Research, University of British Columbia, told the Committee:

*...it is not always possible to establish a causal relationship between mental health problems and the workplace. Sometimes, factors stemming from both work and outside of work can explain the occurrence of mental health problems.*<sup>302</sup>

In a recent article, “Nature and Prevalence of Mental Illness in the Workplace,” Carolyn Dewa and colleagues point out that:

The picture of mental illness in the workplace is becoming increasingly complicated. It is clear that there is a link between mental illness among workers and work-related stress. In turn, both of these are likely to be related to occupation, the work environment and the sex of the worker.

There is also evidence of an association between mental illness and physical disorders. Yet, few studies have considered how all these various factors interact to affect the prevalence of mental disorders among workers. Even fewer have considered their relative contributions to disability in the workplace.<sup>303</sup>

The authors note that many factors contribute to the development of mental illnesses such as depression, but that no one really knows as yet how they all interact:

Yet, the most advanced etiological models of adult depression include factors related to genetic vulnerability, as well as developmental factors, neurobiological factors, childhood experiences, life

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<sup>301</sup> 5 July 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>302</sup> 5 July 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>303</sup> Dewa, C. S., Lesage, A., Goering, P., and Caveen, M. (2004) Discussion Paper: Nature and Prevalence of Mental Illness in the Workplace. *Healthcare Papers*, Vol. 5, No. 2, p. 18.

events, chronic situations (e.g., a stressful work environment) and the presence of other disorders. ...It is not yet understood what the due weight of each of these factors is and how they fit together.<sup>304</sup>

There are many ways of classifying the risk factors that contribute to the development of mental illness. In her testimony to the Committee, Lucie France Dagenais, researcher for the Commission des droits de la personne et des droits de la jeunesse in Quebec, identified two broad categories of risk factor:

*The first are those related to social relations in the workplace. This includes violence, harassment, lack of social support and poor work relations. The second category includes those found in the work organization, which are much less known on an analytical basis. We identified work intensification, lack of flexibility, non-standard work schedules, lack of recognition, lack of expression groups, advancement on the basis of merit and flexibility.*<sup>305</sup>

However, as Michel Vézina and colleagues point out in a recent article, “there is a regrettable absence of scientific consensus on how to define and measure a high-risk psychosocial work environment.” These authors define “psychosocial factors” as those that “refer to all organizational factors and interpersonal relationships in the workplace that may impact health.” Among the factors that “make it possible to document the stressful nature of a work situation” they list:

**There is a regrettable absence of scientific consensus on how to define and measure a high-risk psychosocial work environment.**

— Michel Vézina

...control (latitude, participation, use and development of skills), workload (quantity, complexity and time pressures), roles (conflict and ambiguity), interpersonal relationships (social support, harassment and recognition), career prospects (promotion, precariousness and demotion), organizational climate or culture (communication, hierarchical structure and fairness) and the interaction between work and private life.<sup>306</sup>

Negative attitudes towards mental illness remain widespread throughout society and can compound the difficulties generated by conditions in the workplace. Employers and co-workers may fear people living with a mental disorder; they may think of persons with mental illness as unskilled, unproductive, unreliable, even potentially violent.<sup>307</sup> These unwarranted perceptions may contribute to a reluctance to hire someone with a history of mental illness, or to limit that individual’s career advancement if a previously undisclosed mental illness is revealed. Job loss is also a possible danger for those with the courage to “come out” of the closet at work.

<sup>304</sup> *Ibid.*, p. 20.

<sup>305</sup> 5 July 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>306</sup> Vézina, M., Bourbonnais, R., Brisson, C., and Trudel, L. (2004) Discussion Paper: Workplace Prevention and Promotion Strategies. *HealthcarePapers*, Vol. 5, No. 2, p. 34.

<sup>307</sup> Canadian Psychiatric Association. (2005) Mental Illness and Work. <http://www.cpa-apc.org/MIAW/pamphlets/Work.asp>.

It is important to recognize that this lack of understanding of the relationship between work and mental illness is not only an issue inside the workplace; it extends also to health professionals. Merv Gilbert told the Committee:

*Most mental health providers do not have a clue — I say respectfully — about what goes on in the workplace. Typical GPs faced with a patient coming in tears with a diagnosable disorder and being asked to make decisions about whether or not to stay at work, to return to work, how to deal with workplace issues, often are poorly informed. They may have a poorly written job description in front of them, if they are lucky, on which to make a determination as to whether that person should be at work, how the individual should be accommodated and what kinds of issues should be addressed. Therefore, I strongly suggest we need to educate the health care system as well.*<sup>308</sup>

**It is important to recognize that this lack of understanding of the relationship between work and mental illness is not only an issue inside the workplace; it extends also to health professionals.**

### 8.1.2 The Episodic Nature of Mental Illness

The episodic and cyclical nature of most mental illnesses is another factor that makes it harder to assess the impact of mental illness in the workplace. It creates additional difficulties in making the necessary accommodations at work for people living with mental illness. Unlike other disability groups, people with

**The episodic and cyclical nature of most mental illnesses is another factor that makes it harder to assess the impact of mental illness in the workplace.**

mental illness are rarely ill continuously; rather, they tend to cycle between periods of illness and wellness. When they are symptom-free, they are usually able to work and carry out the normal tasks of life. During episodes of psychiatric illness, however, they may be incapable of functioning at a level that would permit them to work in regular, full-time employment.

The cyclical, episodic, and unpredictable nature of serious mental illness can impede the establishment of a long-term and stable employment history. Having unexplained work-gaps on one's resumé poses a formidable challenge when seeking to return to employment.

### 8.1.3 The Varying Nature of the Relationship Between Mental Illness and Work

People fall into a number of different categories, each of which confronts its own particular challenges with respect to employment-related mental health issues.

In many cases, the onset of a mental disorder occurs in late adolescence or early adulthood, at a time when the affected person's education and training are not yet complete.<sup>309</sup> The process of obtaining qualifications can be interrupted, often never to be resumed. Young individuals in this category are significantly disadvantaged; their lack of skills and qualifications constitute a major and lifelong barrier to future employment.

<sup>308</sup> 5 July 2005, <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/soci-e/rep-e/report1/repintnov04vol1-e.pdf>.

<sup>309</sup> See Chapter 6, Children and Youth.

For others, their careers may be disrupted by serious mental illness or addiction. Many never regain their foothold in the marketplace. For those who do find work, the periods outside the labour force caused by their mental illness often hinder their re-entry.

Three key barriers apply. First, individuals may be subject to discrimination by their employer and/or co-workers. Second, to cope with their illness they may require flexible work arrangements that employers are unwilling, or do not know how to provide. And third, those who have been outside the labour force for extended periods are unlikely to have the type of credentials, skills and employment experience that make them attractive to employers.

Finally, there is the broad category of people who are currently employed but whose productivity is affected to varying degrees by mental health difficulties, a state often referred to as “presenteeism.”

This diversity means that the issue of mental illness, addiction and work has to be explored from a number of different perspectives: making employment accessible to individuals who have never had a job; enabling individuals who have lost their job due to mental illness or addiction to reintegrate into the labour market; and studying how mental illness and addiction affects currently employed individuals.

#### 8.1.4 Many Unanswered Research Questions

A review of current research illuminates how little is known about work-based mental illness and stress-related disorders, in terms either of defining the scope of the problem or establishing best practices to manage it.<sup>310</sup> In a recent article, Elliot Goldner and colleagues note that:

**A review of current research illuminates how little is known about work-based mental illness and stress-related disorders, in terms either of defining the scope of the problem or establishing best practices to manage it**

There has been significant research activity on workplace health that has considered disability management, return to work and treatment. For the most part, however, such research has not directly addressed mental health problems or mental illness but have been focused upon various physical health problems encountered in the workplace (e.g., back injury and other musculoskeletal problems, brain injury, cardiac illness and chronic rheumatic diseases).<sup>311</sup>

They also point out that the paucity of research into mental health at work is not a new phenomenon:

<sup>310</sup> Archambault, E., Cote, G., and Gingras, Y. (2003) Bibliometric Analysis of Research on Mental Health in the Workplace in Canada. Cited in research conducted for the Committee by Neasa M. Martin and Associates, June 2005.

<sup>311</sup> Goldner, E., Bilsker, D., Gilbert, M., Myette, L., Corbiere, M., and Dewa, C. S. (2004) Discussion Paper: Disability Management, Return to Work and Treatment. *Healthcare Papers*, Vol. 5, No. 2, p. 77.

In an article in 1993, Rachel Jenkins asked why mental health at work was so under-researched. More than a decade later, the same question remains relevant. There are many gaps in knowledge to be filled. Little is known regarding best practices in managing the disability associated with the most prevalent mental disorders (i.e., depression, anxiety disorders and substance use disorders). Although some information is available to assist people with severe mental disorders in obtaining employment, knowledge to help people maintain employment is lacking. Additionally, knowledge regarding systemic factors that influence disability management and return to work (e.g., employee assistance programs and disability insurance regulations) relevant to people with mental disorders is yet unavailable.<sup>312</sup>

Importantly, a further barrier to integrated research into mental health at work originates in the fact that specialists in different fields do not always speak the same “language.” This point is well made by Aldred H. Neufeldt:

A major challenge is that much existing knowledge is subject to what might be called an “isolated pockets syndrome.” The different kinds of research...are published in different types of journal, with cross-referencing infrequent. Epidemiological journals examine the relationship between functioning and psychiatric impairment. Occupational psychology and health literature examines topics such as workplace stressors, health, performance and absenteeism. Literature on rehabilitation and psychiatric fields examines specific treatments for psychiatric conditions, along with the effectiveness of interventions such as short- versus longer-hospital stays, supported employment, case management and others.<sup>313</sup>

For employers and employees alike this “language” diversity makes it even harder to establish best practices derived from full reviews of the scientific literature.

## 8.2 THE ECONOMIC IMPACT OF MENTAL ILLNESS IN THE WORKPLACE

To repeat, there are many important gaps in the research into mental health in the workplace. In its interim report, the Committee noted the absence of definitive statistics on the prevalence of mental illness and addiction in the workplace.<sup>314</sup>

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<sup>312</sup> *Ibid.*, p. 86.

<sup>313</sup> Neufeldt, A. H. (2004) Discussion Paper: What Does It Take to Transform Mental Health Knowledge into Workplace Practice? Towards a Theory of Action. *HealthcarePapers*, Vol. 5, No. 2, p. 123.

<sup>314</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.1, p. 107. See also Dewa et al. (2004), p. 13.

Nonetheless, the Committee was informed that disability claims attributable to mental illness have overtaken claims associated with cardiovascular disease as the fastest-growing category of disability costs in Canada. Currently, mental illness and addiction account for 60-65% of all disability insurance claims among selected Canadian and American employers.<sup>315</sup>

Dewa and colleagues report that:

Over the last few years, the number of disability claims for mental disorders has been soaring. Between 1989 and 1994, according to the Health

**Disability claims attributable to mental illness have overtaken claims associated with cardiovascular disease as the fastest-growing category of disability costs in Canada. Currently, mental illness and addiction account for 60-65% of all disability insurance claims among selected Canadian and American employers.**

Insurance Association of America (1995), such claims doubled. In Canada, short- and long-term disability related to mental illness accounts for up to a third of claims and about 70% of the total costs — \$15 to \$33 billion annually.<sup>316</sup>

When compared to all other diseases (such as cancer and heart disease), mental illness and addiction rank first and second in terms of causing disability in Canada, the United States and Western Europe. Of the ten leading causes of disability

**Mental illness and addiction rank first and second in terms of causing disability in Canada, the United States and Western Europe.**

worldwide, five are mental disorders: unipolar depression, alcohol use disorder, bipolar affective disorder, schizophrenia and obsessive-compulsive disorder.<sup>317</sup>

Moreover, as the Global Business and Economic Roundtable on Addiction and Mental Health has pointed out, mental illnesses — depression, anxiety disorders and substance abuse — are concentrated among men and women in their prime working years and among people aged 15 to 24.<sup>318</sup> Those Canadians most likely to experience a mental illness are amongst those at the heart of our working and consuming population.

Mental disorders, unchecked and disabling, impair the capacity of a significant segment of our population to contribute actively to the economy. Innovation and productivity are increasingly key to economic growth and prosperity. Mental disorders should be recognized as a leading source of disability among those we rely on to wield these critical levers of growth and competitiveness.

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<sup>315</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.4, p. 113.

<sup>316</sup> Dewa et al. (2004), p. 22.

<sup>317</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.3, p. 110.

<sup>318</sup> Global Business and Economic Roundtable on Addiction and Mental Health. (2006) Employers Getting Started — The Road to Mental Health and Productivity, Module Three: The Demographics and Distribution of Mental Illness: Mostly an Economic, Business and Labour Cost — Health Care Costs Less Than Productivity Loss.

Productivity is affected both by “presenteeism” — days during which an individual is present at work but functions at less than full capacity — and by absenteeism — days during which an employee did not report to work. Mental illness and addiction are among the most important causes of absenteeism and presenteeism worldwide: a 1998 report of the World Health Organization observed that “more working days are lost as a result of mental disorders than physical conditions.”

In Canada, 20% of the normal work time of employees suffering from an undetected mental illness or addiction is not productive because it is “taken off.” Absenteeism at this rate is four times the rate of unaffected co-workers.<sup>319</sup>

**Those Canadians most likely to experience a mental illness are amongst those at the heart of our working and consuming population.**

Dewa and colleagues point out that:

It has been observed that a significant proportion of the burden of mental disorders arises from presenteeism days...This disability pattern distinguishes mental disorders from chronic physical conditions. Chronic physical conditions are associated with total disability days, while the predominant effect of psychiatric disorders is on partial disability; in fact, psychiatric disorders were responsible for 23 times as many partial disability days as total disability days.<sup>320</sup>

The value of lost productivity in Canada that is attributable to mental illness alone has been estimated at some \$8.1 billion in 1998. More recently, if substance abuse is taken into account as well, that estimate grows to a loss to the economy of some \$33 billion annually. This corresponds to 19% of the combined corporate profits of all Canadian companies, or 4% of the national debt.<sup>321</sup>

The costs of mental disorders in the labour force in Canada fall mostly on employers and employees through their payment of operational, payroll, premiums and out-of-pocket expenses. In statements made to the Global Business and Economic Roundtable on Addiction and Mental Health,<sup>322</sup> a number of major Canadian companies have indicated the extent of the costs of mental disorders in their workforces:

- At CIBC, mental disorders produced absences averaging 95 days, compared to 40 days for other illnesses.

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<sup>319</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.3, p. 110.

<sup>320</sup> Dewa et al. (2004), p. 19.

<sup>321</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.3, pp. 110-111.

<sup>322</sup> Global Business and Economic Roundtable on Addiction and Mental Health. (2006) Module Three.

- Great-West Life Assurance Company estimates that 30% of disability insurance claims relate to mental illnesses, and in the remaining 70%, a quarter or more have mental illnesses as a secondary or underlying diagnosis.

### 8.2.1 The Impact of Global Economic Trends on Mental Health Issues in the Workplace

Two trends, both highlighted by the Global Business and Economic Roundtable on Addiction and Mental Health, are of great significance for how mental health issues in the workplace must be addressed in the 21<sup>st</sup> century.<sup>323</sup>

**If it is true (as it almost certainly is) that we are in the midst of the emergence of a brain-based economy, mental health issues must now become front and centre in the economic affairs of Canada.**

The first — the growing importance of knowledge, and of brain-based skill sets generally, to economic performance — provides a major positive incentive to address mental health issues in the workplace.

The second — the demands imposed by an investment-driven, globally competitive economy — reinforces the first trend in many ways, but it can also be the source of significant risk factors for mental illness in the workplace, in particular by increasing the level of stress placed on employees.

Most new jobs today demand brain-based (cerebral) skills and not the manual ones that were so important to previous generations. If it is true (as it almost certainly is) that we are in the midst of the emergence of a brain-based economy, mental health issues must now become front and centre in the economic affairs of Canada.

This new reality is increasingly recognized at the highest levels of corporate Canada. Gordon Nixon, President and CEO, RBC Financial Group, has been quoted as saying that “this is an economy of mental performance and this defines the capacity of employees to be innovative — to think — a key asset.” Robert MacLellan, Executive Vice-President and Chief Investment Officer of the TD Bank Financial Group, has pointed to the importance of mental health in this context: “High rates of mental illness (brain-based disorders) rob our economy of employee capacity to be productive, innovative.”<sup>324</sup>

The Honourable Michael Wilson, former special advisor to the Health Minister on mental health in the federal government workplace, has formulated what the Global Business and Economic Roundtable on Addiction and Mental Health calls “The Wilson Principle”:

We have seen tremendous progress in preventing physical injuries and illnesses at work. The safety records of companies I am associated with are a source of great pride to them. I strongly encourage employers to build on these achievements.

<sup>323</sup> Global Business and Economic Roundtable on Addiction and Mental Health. (2006) Employers Getting Started — The Road to Mental Health and Productivity, Module Two: The Building Blocks of Productive Capacity in a Brain-Based Economy — Setting the Stage for Mental Health in the Workplace.

<sup>324</sup> *Ibid.*

It would be a shame to un-do 30 years of great progress in physical health and safety as a result of massive losses of productive capacity due to untreated mental illness in the workplace, especially depression.<sup>325</sup>

Evolution of the economy has thus produced a new and costly convergence — the advent of a brain-based economy at the same time that brain-based disorders are becoming the principal cause of disability in the labour force.

**Evolution of the economy has thus produced a new and costly convergence — the advent of a brain-based economy at the same time that brain-based disorders are becoming the principal cause of disability in the labour force.**

However, the implications of this new reality are not always immediately apparent, especially given the second trend mentioned above. The tendency for business to face intense pressure, especially from investors, to maximize shareholder value has led some companies to lay people off, and to struggle to “do more with less.” Beyond the tremendous human costs for the people involved in massive corporate downsizing, it is also important to recognize the possible longer-term consequences of this strategy for the enterprises themselves.

**There is thus a strong and compelling business case to be made for making the workplace an environment that is conducive to mental health.**

In an economy that puts a premium on workplace productivity and innovation, the prudent deployment of human capital is critical to competitive success. Human capital is really productive capacity. In an economy based on the mental performance of employees, the capacity to think, concentrate and innovate is critical. Strategies that undermine this capacity are likely to have detrimental effects on the long-term interests of the corporations that engage in them.

There is thus a strong and compelling business case to be made for making the workplace an environment that is conducive to mental health, since the payback in greater productivity will outweigh the costs of the investment required to significantly reduce mental health risk factors in the workplace.

### 8.3 WORKPLACE-BASED INITIATIVES

There are two broad categories of mental health intervention in the workplace. First, primary prevention measures aim to eliminate, or at least reduce, factors in the workplace that have a negative impact on the mental health of the workforce. Second, there is a range of secondary intervention strategies designed principally to reduce the effects of stressful work situations by improving the ability of individuals to adapt to and to manage stress.

**Preventative Intervention research identifies work-related causes that must be addressed in order to reduce or eliminate stress.**

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<sup>325</sup> *Ibid.*

### 8.3.1 Primary Prevention

There is evidence to indicate that well-structured organizational approaches generate more important, longer-lasting effects than secondary intervention strategies directed at individuals.<sup>326</sup> Preventative intervention research identifies work-related causes that must be addressed in order to reduce or eliminate stress. Two risk models identify those psychosocial and interpersonal relationship factors that contribute to making people sick: 1) Karasek's "job demand-control-support" and 2) Siegrist's "effort/reward imbalance" models.

The "job demand-control-support" model is based on the finding that a work situation characterized by a combination of high psychological demands and low decision latitude increases the risk of developing physical and mental health conditions.<sup>327</sup> The

**Interventions focused on organization of work can have considerable benefits, notably decreased absenteeism and symptoms of depression, and even increased well-being and productivity.**

"effort/reward imbalance" model is based on the finding that a work situation characterized by a combination of high effort and low reward can be accompanied by emotional and physiological reactions that can have a negative impact on mental health.<sup>328</sup>

While "control" is central to the Karasek model, "social reciprocity" (i.e., the possibility of having access to legitimate advantages, duly earned in the process of performing the work) is the key concept for Siegrist's model. Siegrist's model is particularly well adapted to measuring the impact on mental health of a major characteristic of workplace changes in the past decade, namely, reduced security of employment.<sup>329</sup>

Various studies have identified workplace attributes that contribute both to profitability and to better mental health, including: employment security, self-managed teams and decentralized decision-making, extensive training, reduced status distinctions, and reduced barriers to sharing financial and performance information across the organization. Vézina and his colleagues refer to studies that identify five factors that are necessary for the success of a primary intervention project. They are:

...support from senior management and involvement of all of the hierarchy; employee participation in discussions of problems and possible solutions; preliminary identification of worker populations at risk on the basis of validated theoretical models or their associated manifestations; rigorous implementation of necessary changes in targeted worker populations; on-site management of the procedure and changes.<sup>330</sup>

Studies have shown that if those factors are in place, interventions focused on organization of work can have considerable benefits, notably decreased absenteeism and symptoms of depression, and even increased well-being and productivity. Despite this empirical evidence

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<sup>326</sup> Vézina et al. (2004), p. 39.

<sup>327</sup> *Ibid.*, p. 34.

<sup>328</sup> *Ibid.*, p. 36

<sup>329</sup> *Ibid.*

<sup>330</sup> Vézina et al. (2004), pp. 39-40.

to support the health impact of these models, however, few comprehensive workplace intervention strategies have been implemented.

The Global Business and Economic Roundtable on Addiction and Mental Health has identified 10 management practices or behaviours that can precipitate or aggravate mental health problems in the workforce:

1. Imposing unreasonable demands on subordinates and withholding information materially important to them in carrying out their jobs.
2. Refusing to give employees reasonable discretion over the day-to-day means and methods of their work.
3. Failing to credit or acknowledge their contributions and achievements.
4. Creating a treadmill at work — too much to do, all at once, all the time.
5. Creating perpetual doubt, employees never sure of what’s happening around them.
6. Allowing mistrust to take root. Vicious office politics disrupt positive behaviour.
7. Tolerating, even fostering, unclear company direction and policies, job ambiguity and unclear expectations.
8. Sub-par performance management practices — specifically employee performance reviews — even good ones — which fail to establish the employee’s role in the company’s near or mid-term future.
9. Lack of two-way communication up and down the organization.
10. Managers rejecting, out of hand, an employee’s concerns about workload.<sup>331</sup>

The Committee agrees with the Roundtable that a successful primary intervention strategy must attempt to modify these unhelpful practices, and therefore recommends:

31	<b>That the Canadian Mental Health Commission (see Chapter 16) work with employers to develop and publicize best management practices to encourage mental health in the workplace.</b>
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<sup>331</sup> Global Business and Economic Roundtable on Addiction and Mental Health. (2004) Roundtable Roadmap to Mental Disability Management.

### 8.3.2 Secondary Intervention

Three types of secondary intervention are of particular importance: (1) disability management; (2) workplace accommodations; and (3) Employee Assistance Programs (EAPs).

#### 8.3.2.1 Disability Management

Workplace disability management is widely used to return people with physical disabilities to the workplace. Factors found to enhance return to work are: employer participation, a supportive work climate, and cooperation between labour and management. Although widely practiced in association with physical conditions, disability management programs are relatively new to the mental health field and are too little studied to determine their effectiveness.<sup>332</sup>

**The lack of “mental illness literacy” amongst employees, managers and supervisors also reduces the likelihood of speedy identification and resolution of mental health and addictions problems in the workplace.**

Managing disability within the workplace can be complex, given that it is a shared responsibility of the worker, supervisors and managers, employee assistance programs, human resource managers, and the public health system.<sup>333</sup> The lack of “mental illness literacy” amongst employees, managers and supervisors also reduces the likelihood of speedy identification and resolution of mental health and addictions problems in the workplace.

A further challenge stems from the fact that the health care system and the workplace are very different, with differing cultures, languages, practices and priorities. The differing conceptual frameworks used by mental health and occupational health professionals can create gaps in understanding, that can lead to a poor coordination of services and result in delays in returning people to work.<sup>334</sup> Creating common goals, a shared understanding and a common language that will allow information to be shared and knowledge to be conveyed across different systems is essential. What is needed are boundary walkers — leaders who are versed in both mental health and employer issues and who can help to integrate disparate systems more effectively over time.

The Committee therefore recommends:

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<sup>332</sup> Neufeldt (2004).

<sup>333</sup> Gnam, W. (2004) Researcher Response: Research Priorities Are Critical. *HealthcarePapers*, Vol. 5, No. 2, pp. 91-94.

<sup>334</sup> Bender, A., and Kennedy, S. (2004) Discussion Paper: Mental Health and Mental Illness in the Workplace: Diagnostic and Treatment Issues. *HealthcarePapers*, Vol. 5, No. 2, pp. 54-67.

- 32 That the Knowledge Exchange Centre to be created as part of the Canadian Mental Health Commission (see Chapter 16) assist employers, occupational health professionals and mental health care providers in developing a common language for fostering the management of mental illness in the workplace and in sharing best practices in this area.

### 8.3.2.2 Workplace Accommodations

Accommodation refers to “any modification of the workplace, or in the workplace procedures, that makes it possible for a person with special needs to do a job.”<sup>335</sup> Just as individuals with physical disabilities may require physical aids or structural changes to the workplace, individuals with mental disorders most often require social and organizational accommodations to be made.

Generally these involve changes to the way things have traditionally been done in a particular workplace. Permitting someone with a mental illness to work flexible hours, for example, provides him or her access to employment in the same way a ramp does for an individual in a wheelchair. Accommodation means, in effect, providing equitable treatment for individuals with disabilities, regardless of their type and source.

**Accommodation means providing equitable treatment for individuals with disabilities, regardless of their type and source.**

**There is no comprehensive list of the accommodations needed by people who are dealing with mental health issues, nor is there research that defines “best practice” approaches.**

According to the Canadian Psychiatric Association,<sup>336</sup> accommodation should be built on positive arrangements that promote equality in employment, including:

- Creating an environment in which arrangements are made in relation to the individual needs of each employee;
- Respecting the employee’s desire for confidentiality as well as identifying the specific form and the degree of confidentiality required;
- Being willing to engage in joint problem solving;
- Making all arrangements voluntary for the employee, and being prepared to review plans periodically to meet changing needs;

<sup>335</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.5.2, p. 123.

<sup>336</sup> *Ibid.*, p. 124.

- Being flexible in enforcing traditional policies;
- Being concrete and specific when identifying accommodations that are made. Putting them in writing is a good idea.

One study followed 240 persons with serious mental illnesses over a 10-year period who were able to maintain gainful employment, largely because formal work reintegration programs were in effect. These individuals earned \$5 million, paid \$1.3 million in income taxes, and saved the government an estimated \$700,000 in welfare costs. The result was a net \$2-million increase in collective wealth.<sup>337</sup>

**There is no comprehensive list of the accommodations needed by people who are dealing with mental health issues, nor is there research that defines “best practice” approaches.**

According to Mental Health Works, CMHA Ontario,<sup>338</sup> there is no comprehensive list of the accommodations needed by people who are dealing with mental health issues, nor is there research that defines “best practice” approaches. Accommodation requires consideration of the individual needs of employees and the resources available to the employer. In any case, as systemic barriers are removed, the need for individual accommodation will decrease. For example, flextime programs can benefit all employees, while also allowing an employee with a mental illness who needs to modify his or her hours of work to do so without having to ask for any special further accommodation to be made.

The duty to accommodate is not the employer’s alone — trade unions share this responsibility. In the Committee’s view, the interests of the employee are best served when management and unions work cooperatively in accommodating the return to work through job modifications and other such arrangements. In this context, it is important for all parties to remind themselves that the return to work process is, in effect, part of the recovery process for employees living with a mental disorder.

**It is important for all parties to remind themselves that the return to work process is, in effect, part of the recovery process for employees living with a mental disorder.**

#### 8.3.2.2.1 Other Mental Health Accommodations

Other possible mental health accommodations include the following.

##### Flexible scheduling

- Part-time shifts (which may be used to return a worker to a full-time position).
- More frequent breaks.

<sup>337</sup> Harnois, G., and Gabriel, P. (2000) *Mental Health and Work: Impact, Issues and Good Practices*. Joint publication of the World Health Organization and the International Labour Organization, Geneva, p. 19.

<sup>338</sup> Mental Health Works, CMHA Ontario. <http://www.mentalhealthworks.ca/index.asp>.

### Changes in supervision

- Modifying the way instructions and feedback are given. For example, written instructions may help an employee focus on tasks.
- Having weekly meetings between the supervisor and employee may help to deal with problems before they become serious.

### Changes in training

- Allowing extra time to learn tasks.
- Allowing the person to attend training courses that are individualized.

### Modifying job duties

- Exchanging minor tasks with other employees.

### Modifying work space or changing location

- Allowing an employee to relocate to a quieter area where he or she will be free from distractions.
- Allowing an employee to work at home.

#### ***8.3.2.3 Employee Assistance Programs (EAPs)***<sup>339</sup>

EAPs are employer-sponsored programs designed to alleviate and assist in eliminating a variety of workplace problems. The source of these problems can be either personal (legal, financial, marital or family-related, mental health problems and illnesses, including addiction) or work-related (conflict on the job, harassment, violence, stress, etc.).

**EAPs have become the primary portal through which working Canadians often get their first access to mental health care and addiction treatment.**

Typically, EAPs provide counselling, diagnostic, referral and treatment services. Those staffing EAP programs usually hold a degree in a mental health or social service discipline (social work, psychology, psychiatry, counselling and/or marital and family therapy). Some services may also be contracted out to qualified persons.

EAP services are available both in private and public organizations and are usually administered completely independently of other programs within the organization. Confidentiality is the cornerstone of an effective EAP. The anonymity of clients, the confidentiality of interviews, the maintenance, transfer and destruction of files are subject to applicable federal and provincial laws that define the conduct of counsellors. Generally,

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<sup>339</sup> This section is drawn largely from: Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, pp. 121-23.

information may be released by an EAP counsellor only in situations in which the client has provided informed and signed consent specifying what information is to be released and to whom.

The Committee was told that between 60% and 80% of Canadians who are employed in a medium-sized or large company (over 500 employees) currently have access to some form of EAP. According to Rod Phillips, President and CEO, Warren Shepell Consultants Corporation, EAPs are very effective; they have become the primary portal through which working Canadians often get their first access to mental health care and addiction treatment:

In many cases, in our experience, you would have about 85 per cent of the people who we see in a given year getting sufficient treatment through the EAP program that they would require no further treatment. About 15 per cent of the people would then be referred into community programs or into the public health care system.<sup>340</sup>

EAPs also have a strong prevention component. Much of the work being done with employers focuses on wellness and other programs that support a healthy mental health work environment.

EAPs have been widely adopted across North America and are positively regarded by employers and employees.<sup>341</sup> They have certain limitations, however. For example, Ash Bender and his colleagues<sup>342</sup> expressed concern about the number of therapeutic sessions being offered to EAP clients; based on anecdotal evidence, these have decreased dramatically from seven per individual to fewer than three over the last 10 years. The authors concluded that the likelihood is low of effectively addressing any serious substance abuse or mental illness problem in this limited therapeutic time frame. This concern requires particular attention.

Mary-Ann Baynton, Director, Canadian Mental Health Association in Ontario, suggested to the Committee that it would be helpful if EAPs were able to provide people with access to “advocates” who could assist them in a variety of ways:

*That leads to the last recommendation, which is that we should have advocates. Many times, employers will say that they sent out the forms and people never filled them out or called back, they are not doing their part. The employers do not understand that the mental illness itself often makes it impossible for the person to get out of bed, never mind fill out a complicated set of forms. We are looking into having an advocate who can do this on behalf of people with*

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<sup>340</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.5.1, p. 122.

<sup>341</sup> Neufeldt (2005).

<sup>342</sup> Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, section 6.5.1, p. 123.

*mental health issues. However, it could be something that the EAPs or the employers themselves could provide.*<sup>343</sup>

With regard to EAPs, the Committee recommends:

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| 33 | <p>That employers increase the number of counselling sessions offered through Employee Assistance Programs (EAPs), especially in communities where access to other mental health services is limited.</p> <p>That research be undertaken to evaluate EAPs, and that the results be shared through the Knowledge Exchange Centre that the Committee recommends be created as part of the Canadian Mental Health Commission (see Chapter 16), with a view to strengthening the effectiveness of these programs.</p> |
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## 8.4 TRAINING OPPORTUNITIES

Canadians with serious mental illness have relied heavily on community vocational rehabilitation programs that have often struggled to obtain adequate funding. The limited research that has been done suggests that not all vocational rehabilitation approaches achieve the same degree of success in moving people into employment.<sup>344,345,346</sup>

### 8.4.1 Vocational Rehabilitation Programs

Vocational rehabilitation programs are intended to help people become or remain economically independent through work. Specialized vocational rehabilitation programs include career counselling, work assessment, work adjustment and conditioning programs, temporary employment and transitional employment placement.

**Vocational rehabilitation programs are intended to help people become or remain economically independent through work.**

Research into vocational rehabilitation is limited in scope and tends to be descriptive and anecdotal. The assumption behind most vocational rehabilitation is that careful planning combined with a supported and slow re-entry into the workforce will increase the

**The evidence available, however, suggests strongly that moving people quickly towards employment is more effective than a gradual, slow re-entry.**

<sup>343</sup> 5 July 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/25ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>344</sup> Shankar, J., and Collyer, F. (2002) Support needs of people with mental illness in vocational rehabilitation programs — the role of the social network. *International Journal of Psychosocial Rehabilitation*, Vol. 7, 15-28.

<sup>345</sup> Lehman, A. F. (1995) Vocational Rehabilitation in Schizophrenia. *Schizophrenia Bulletin*, Vol. 21, No. 4, 645-656.

<sup>346</sup> Marrone, J., and Gold, M. (1995) Employment Supports for People with Mental Illness. *Psychiatric Services*, Vol. 46, No. 7, 707-711.

likelihood of success. The evidence available, however, suggests strongly that moving people quickly towards employment is more effective than a gradual, slow re-entry. The longer the delay, the greater the risk in reducing employability through insufficient work experience.<sup>347</sup>

An additional barrier to employment includes relegating people with mental illness to entry-level, low-wage fields where they often experience little economic progress even when their job retention rates are similar to those of people without disabilities. Minimal expectations by staff, paternalistic protectionism that shields clients from failure, and lack of outcome accountability have all contributed to the low success rate of vocational rehabilitation programs.<sup>348</sup>

### 8.4.2 Supported Employment

In the mid-1980s, a new approach to employment emerged, known as supported employment. Its emergence was prompted by a concern to avoid models that tended to foster dependency and to reduce the need for mental health clients to compete in the job market for employment. Supported employment involves placing clients as quickly as possible into jobs without any extensive preparation, while simultaneously providing ongoing, intensive on-the-job support and training using assigned job coaches.

**Supported employment involves placing clients as quickly as possible into jobs without any extensive preparation, while simultaneously providing ongoing, intensive on-the-job support and training using assigned job coaches.**

**Supported employment models have produced more positive outcomes than traditional vocational rehabilitation services.**

A comparative research review indicates that supported employment models have produced more positive outcomes than traditional vocational rehabilitation services, brokered vocational rehabilitation services, day treatment programs, pre-vocational programs, or sheltered workshops.<sup>349</sup> Reviewing 18 randomized control trials, researchers found that people participating in supported employment programs were significantly more likely to be employed than those who received pre-vocational training (at 12 months, 34% of those in supported employment were employed, compared with only 12% who had pre-vocational training).<sup>350</sup> It is important to note however, that this success rate (34%), although positive, remains relatively modest.

### 8.4.3 Consumer Economic Development Initiatives

Consumer development initiatives emerged in the 1990s as a response by people living with mental illness to the failure of traditional vocational rehabilitation programs to help them achieve their employment goals. People living with mental illness began to develop

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<sup>347</sup> Marrone, J., and Golowka, E. (1999) If Work Makes People Sick, What do Unemployment, Poverty and Social Isolation Cause? *Psychiatric Rehabilitation Journal*, Vol. 23, No. 2.

<sup>348</sup> *Ibid.*

<sup>349</sup> Bond, G. R., Drake, R. E., Mueser, K. T., and Becker, D. R. (1997) Supported employment for people with severe mental illness: A review. *Psychiatric Services*, Vol. 48, No. 3, 335-346.

<sup>350</sup> Crowther, R., Marshall, M., Bond, G., and Huxley, P. Vocational rehabilitation for people with severe mental illness. *The Cochrane Database of Systematic Reviews* 2001, Issue 2, Art. No.: CD003080. DOI: 10.1002/14651858.CD003080.

businesses which they both owned and operated. The underlying belief was that, if given the tools, they could play an important role both in supporting themselves and in advocating for mental health services and supports that are more effective and accountable.<sup>351</sup>

These initiatives have included self-help organizations in which peer counselors facilitated mutual aid and education initiatives, as well as diverse consumer-run businesses which offered employment opportunities and business development skills to mental health consumers. The research done on consumer-run initiatives demonstrates that this is a promising avenue to move people living with serious mental illness into the workforce.<sup>352</sup>

#### 8.4.4 The Club House Model

In many jurisdictions, Club Houses continue to be a mainstay in funded community service delivery. Initially developed in the 1940s by former psychiatric patients, the goal was to help others make the transition from hospital to community.<sup>353</sup> Club

**The research done on consumer-run initiatives demonstrates that this is a promising avenue to move people living with serious mental illness into the workforce**

Houses offer vocational opportunities, problem-solving groups, case management, recreational activities, and academic preparation.<sup>354</sup> They operate under egalitarian rules and are run by staff and clients who seek to provide an accepting, culturally sensitive environment where people can socialize, mutually support each other and gain experience in graded employment opportunities to prepare them for their return to competitive employment.<sup>355</sup>

Pre-vocational training programs are intended to assist people living with mental illness to make the transition to employment through a two-step process. Phase one is the provision of a “work ordered day” where clients work in teams with staff to operate and manage the Club House. The second phase is an opportunity to participate in transitional employment programs where clients are placed in a series of paid but temporary jobs controlled by the Club House. Despite the longevity and continued popularity of this concept, however, there is, however, limited evidence of the efficacy of Club Houses in achieving their vocational goals.

#### 8.4.5 Sheltered Workshops

Widely used up until a decade ago, sheltered workshops now primarily serve the needs of developmentally delayed adults, although some provinces continue to include sheltered workshops in their community-based rehabilitation programs for people with mental illness. The little

**Sheltered workshops now primarily serve the needs of developmentally delayed adults.**

<sup>351</sup> Ontario Peer Development Initiative. (October 2003) The History of OPDI.  
[http://www.opdi.org/about\\_us.html#history](http://www.opdi.org/about_us.html#history).

<sup>352</sup> Danley, K. (1996) Proceedings of the Conference on Psychological Disabilities in the Workplace.

<sup>353</sup> The National Mental Health Consumers Self-Help Clearing House.

<sup>354</sup> McReynolds, C. (2002) Psychiatric Rehabilitation: The Need for a Specialized Approach. International Journal of Psychosocial Rehabilitation, Vol. 7, 61-69.  
[http://www.psychosocial.com/IJPR\\_7/approach.html](http://www.psychosocial.com/IJPR_7/approach.html).

<sup>355</sup> Clubhouse History. <http://www.telusplanet.net/public/club1/history.html>.

research that has been done shows a low success rate (in the range of 5-10%) in assisting people living with a mental illness to obtain non-sheltered employment. In fact, participation in sheltered workshops may further entrench in those involved and the general public alike low expectations of the capacity of people with mental illness to work.

#### 8.4.6 Federal Initiatives

The Opportunities Fund for Persons with Disabilities was originally created as a pilot program in 1997, as part of the Government of Canada's response to the report of the Federal Task Force on Disability Issues (the Scott report) in 1996. Funding for the Opportunities Fund became permanent in December 2000 and is administered by Social Development Canada.

**The Opportunities Fund is an employability program for people with disabilities who have had little or no attachment to the labour force. Its objective is to help these people prepare for, get and keep jobs, or to become self-employed.**

The Opportunities Fund is an employability program for people with disabilities who have had little or no attachment to the labour force. Its objective is to help these people prepare for, get and keep jobs, or to become self-employed. To meet this objective, the government works in partnership with non-governmental organizations that represent people with disabilities, with the private sector and with provincial governments.

The Opportunities Fund supports initiatives that:

- encourage employers to hire workers with disabilities;
- help people with disabilities build their employment skills, integrate into the labour market and/or become self-employed;
- provide opportunities for work experience that could lead to stable employment; and
- improve access to employment or employment services by providing personal support.

The Opportunities Fund now serves about 4,500 people with disabilities a year, although it is not known what percentage of these are people living with mental illness.

**One of the Opportunities Fund's strengths is its individual, flexible approach to delivering services to clients.**

According to an evaluation conducted in 2001, one of the Opportunities Fund's strengths is its individual, flexible approach to delivering services to clients. Assessments from Opportunities Fund participants, as well as the outcome data, have also shown that the program has helped individuals find work and has improved their employability and quality of life.

The Committee recommends:

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| 34 | <p>That the Department of Human Resources and Social Development, through the Opportunities Fund for Persons With Disabilities, facilitate the establishment of a nation-wide supported employment program to assist persons living with a mental illness to obtain and retain employment.</p> <p>That this program promote the development of, and provide support for, alternative businesses that are both owned and operated by persons living with mental illness.</p> <p>That the Department of Human Resources and Social Development report on how many people living with mental illness are assisted through the Opportunities Fund for Persons With Disabilities</p> |
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## 8.5 INSURANCE AND INCOME SUPPORT

### 8.5.1 Workers' Compensation Boards<sup>356</sup>

In all provinces and territories, Workers' Compensation Boards (WCBs) receive an increasing number of mental health-related claims (referred to as "occupational stress"); and in a growing number of cases, the Boards have provided compensation for such claims.

**A major issue raised with respect to compensation by WCBs concerns the fact that, regardless of jurisdiction, it is more difficult to prove the genesis of a mental disorder than that of a physical illness. As a result, there is some controversy about whether and how mental disorders should be covered under workers' compensation schemes.**

A review of occupational stress claims reported to WCBs was undertaken by the Association of Workers' Compensation Boards of Canada to find out how many types of claims were filed on an annual basis, whether they were of an episodic or chronic nature, and how much compensation was paid in each case. This review proved to be very difficult. In many cases, the Boards do not collect this type of data, or if they do, the data are not comparable because the definitions employed by each WCB may be different (see Table 8.1). The review could not, therefore, provide a national perspective on the number of claims resulting from occupational stress and the associated costs of compensation.

Terry Bogyo, Director of Corporate Planning, Workers' Compensation Board of B.C., explained to the Committee that provincial and territorial variations in the treatment of stress disorders was a consequence of the different legislative frameworks that exist in each jurisdiction:

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<sup>356</sup> This section is drawn largely from: Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, pp. 116-118.

*...It is not reluctance on the part of the boards to provide the benefit, because the boards do what the legislation tells us to do. We are the body that gives life to the legislation. ...That variability goes back to the responsibility of legislators to design legislation that is responsive to the social, political, economic, cultural and historical values that are inherent to that jurisdiction. Whether it is right is not for the boards to say. It is our job to administer that legislation. It is not a matter of reluctance. If the legislation says that we cover it, then indeed it would be covered by us.*<sup>357</sup>

A major issue raised with respect to compensation by WCBs concerns the fact that, regardless of jurisdiction, it is more difficult to prove the genesis of a mental disorder than that of a physical illness. As a result, there is some controversy about whether and how mental disorders should be covered under workers' compensation schemes. Under the occupational disease model used by WCBs, compensation for a disability is based on whether the disability arises from continuous exposure to hazardous conditions related to an individual's employment. Yet, as we have seen, most advanced etiological models of mental disorders include a variety of factors, such as genetic vulnerability, developmental circumstances and neurobiological factors, in addition to factors such as a stressful work environment. The relative weight of each of these dimensions is not yet understood, nor is it clear how they fit together.

The Committee believes that it is important for all concerned parties to address these issues and recommends:

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| 35 | <p><b>That the Canadian Mental Health Commission (see Chapter 16) work closely with provincial and territorial governments as well as with Workers' Compensation Boards, employers and trade unions across the country to develop best practices with respect to compensation for occupational stress-related claims.</b></p> |
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### 8.5.2 Employer-Sponsored Disability Insurance Plans

Two types of disability income insurance plans are offered by employers: short-term disability (STD) and long-term disability (LTD). STD plans replace a percentage of pre-disability employment earnings (70%, for example) for periods of less than one year's duration (e.g., six months). They are generally harmonized with sick leave, other employee benefits and Employment Insurance (EI) benefits, providing continuity of income for the plan member who has suffered a disabling illness or injury.

**Disability income insurance plans are designed to ensure that there is a financial incentive for recipients to return to work.**

<sup>357</sup> 20 April 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

**TABLE 8.1**  
**WORKERS' COMPENSATION BOARDS IN CANADA: INTERJURISDICTIONAL**  
**COMPARISON OF OCCUPATIONAL STRESS COMPENSABILITY**

<b>Alberta</b>	<p>Compensation for occupational stress provided if:</p> <ul style="list-style-type: none"> <li>▪ there is a confirmed diagnosis under the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders;</li> <li>▪ the work-related events or stressors are the predominant cause of the injury;</li> <li>▪ the work-related events are excessive or unusual in comparison to the normal pressures experienced by the average worker in a similar occupation; and</li> <li>▪ there is objective confirmation of the events.</li> </ul>
<b>British Columbia</b>	<p>Compensable forms of stress include:</p> <ul style="list-style-type: none"> <li>▪ stress caused by a sudden and unexpected traumatic event; and</li> <li>▪ stress that results from a compensable injury such as severe anxiety following the amputation of a leg.</li> <li>▪ Stress that is caused by the pressures encountered in daily personal and work life is not compensable.</li> </ul>
<b>Manitoba</b>	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
<b>New Brunswick</b>	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
<b>Newfoundland and Labrador</b>	Legislative definition of injury covers stress only where it results from an acute reaction to a sudden and unexpected traumatic event and to exclude stress due to labour relations issues.
<b>NWT &amp; Nunavut</b>	Claims for occupational stress are considered on a case-by-case basis.
<b>Nova Scotia</b>	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
<b>Ontario</b>	<p>Mental stress is compensable in respect of situations where there is an acute response to a sudden and unexpected traumatic event arising out of and in the course of employment.</p> <p>Mental stress due to the employer's employment decisions does not entitle a worker to benefits.</p>
<b>Prince Edward Island</b>	Definition of accident/occupational disease excludes stress except as an acute reaction to a traumatic event.
<b>Quebec</b>	Stress is compensable if the worker can show a relationship between the illness and the work or a risk in the work.
<b>Saskatchewan</b>	Compensation for occupational stress is specifically allowed for as a matter of policy where clear and convincing evidence is provided that the work stress was excessive and unusual; routine industrial relations actions taken by the employer are considered normal and not unusual.
<b>Yukon</b>	Post-traumatic stress considered compensable under legislation; current practice is to assess all other stress-related claims on a case-by-case basis.

Source: Kishchuk, P. (March 2003) Expansion of the Meaning of Disability. Paper commissioned by the Yukon Workers' Compensation Board, p. 12.

LTD plans focus on longer periods of disability. They typically commence payments after the disabled individual has been off work for a significant period, such as six months, and replace a specified percentage of the person's

**Employers, managers and insurers must become more knowledgeable about mental illness and addiction in order to better manage disability claims.**

pre-disability employment income, for example 70%. LTD benefits typically run for up to two years for recipients who are unable to perform their own jobs, and can continue to a limit of age 65 or the onset of retirement benefits for recipients who cannot perform their own or any reasonably comparable job. LTD benefits provided by the employer's plan may be reduced by the amount obtained by the recipient under the Canada Pension Plan (Disability) (CPP(D) — see below).

An important aspect of both STD and LTD plans is the commitment to assist recipients to return to the workplace, preferably to their own jobs, or to another job if that proves not to be feasible. Consistent with this commitment, disability income insurance plans are designed to ensure that there is a financial incentive for recipients to return to work; thus disability income replacement benefits do not exceed, and are usually less than, pre-disability employment income. Disability insurance should not be a disincentive to work. In this context, the Canadian Psychiatric Association explained:

Disability insurance for any illness requires a precise definition of that illness. Whereas it is important that disabled psychiatric patients receive an adequate income to protect themselves from serious financial reverses over the time that they are not able to work, it is just as important to recognize that disability payments may constitute a major secondary gain actually impeding a patient's progress and delaying rehabilitation. There are two factors to be considered: a) the prevalent misconception that work is ipso facto stressful and likely to aggravate a diagnosed psychiatric disorder; and b) the recognition that some patients who have undergone a serious psychiatric disorder may want to avoid exposure to what they presume to be stressful factors at work because of lack of confidence even after they have improved clinically. It should be recognized that return to work as soon as possible is likely to improve the patient's self-esteem, reestablish him/her in a familiar social network and otherwise aid rehabilitation. There is some evidence that work deprivation may be one of the causes of psychiatric disorder.<sup>358</sup>

Employers, managers and insurers must become more knowledgeable about mental illness and addiction in order to better manage disability claims. During a recent speech, Bill Wilkerson, co-founder and CEO, Global Business and Economic Roundtable on Addiction and Mental Health, commented:

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<sup>358</sup> Canadian Psychiatric Association. (1988) Insurability of the Psychiatrically Ill or Those With a Past History of Psychiatric Disorder. Position Paper.

[The insurance] industry must develop a perspective based on knowledge of mental health issues. Like business generally, the insurance sector needs a mental health education agenda.

An example of where this is especially true is in the comorbidity of mental illness and physical chronic diseases as this pertains to: origin and the duration of human disability; the complexity, lengths and risks of treatment and recovery; and, the pace and timing of the sufferer's return to work.

The insurance industry needs — at the levels of claims management — to know more about the medical science of mental health. ... The industry needs to develop a knowledge base about the expanding universe of neuroscience and its illumination of the origins of behaviour.

### 8.5.3 Provincial and Territorial Social Assistance Programs

Insurance and income support programs provide some level of protection for persons living with mental illness who find themselves unable to work. However, programs operated by workers' compensation boards, employers, and the Government of Canada (e.g., CPP(D) and EI) share a key attribute — to qualify, individuals must have a job, often for a prolonged period of time. This, coupled with a myriad of other eligibility criteria and time-limited benefits, frequently results in people living with mental illness having to turn to the income assistance programs of last resort — social assistance (i.e., welfare) programs operated by the provinces and territories.

**Strict eligibility criteria, including a requirement to first exhaust one's own financial assets, are not the only problem associated with social assistance programs for persons with disabilities. Benefits, while generally higher than those available under general welfare assistance programs, remain at a level that may result in financial hardship.**

Most often, social assistance programs distinguish between individuals who are able to work but unable to find employment, and those who are unable to work due to illness, disability or other cause. For example, the Government of Ontario operates the Ontario Works program to assist those persons who are able to work but unable to find employment. Here, applicants are expected to first use up their personal assets before they become eligible for assistance. Benefit levels are low, and recipients are required to participate in retraining or other "employment activities." In short, "eligibility rules are designed to ensure that people turn to welfare only when all other financial resources have been exhausted."<sup>359</sup>

In contrast, those who are unable to work may be streamed into the Ontario Disability Support Program (ODSP). Benefit levels are roughly twice those of Ontario Works, and while recipients are encouraged to work to the greatest extent possible, participation in

<sup>359</sup> Government of Ontario, Ministry of Community and Social Services. Who is Eligible for Ontario Works? <http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioWorks/FAQs/OW-q-eligibility.htm>.

related programs, such as retraining, is voluntary. Also, applicants may retain a small amount of personal assets, some \$5,000 in cash and RRSPs.<sup>360</sup>

Unfortunately, as is the case with other income support programs, eligibility for ODSP is restricted. Applicants must “have a substantial physical or mental impairment that is continuous or recurrent and is expected to last one year or more.” Given the cyclical and unpredictable nature of mental illness, persons living with mental illness, and unable to work, may find themselves ineligible for ODSP. They are thus forced instead to rely on Ontario Works, even though they are not the target group for this program.

**Those who seek to return to work may be dissuaded by policies that would result in varying amounts of earned income being deducted from their benefit cheques, a loss of specific benefits (i.e., medical or drug benefits) or a loss of benefits altogether.**

Strict eligibility criteria, including a requirement to first exhaust one’s own financial assets, are not the only problem associated with social assistance programs for persons with disabilities. Benefits, while generally higher than those available under general welfare assistance programs, remain at a level that may result in financial hardship. The following table includes a sampling of assistance rates and earning exemption amounts (i.e., the amount that can be earned before benefits are reduced) from across Canada:

	British Columbia	Ontario	Quebec
Amount per month for a single person with a disability	\$856.42 <sup>361</sup>	\$959.00 <sup>362</sup>	\$835.67 <sup>363</sup>
Earning Exemption Amount	\$400.00 <sup>364</sup>	\$160.00 <sup>365</sup>	\$100.00 <sup>366</sup>

<sup>360</sup> Government of Ontario, Ministry of Community and Social Services. ODSP Handbook. [http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP\\_handbook.htm](http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm).

<sup>361</sup> Government of British Columbia, Ministry of Employment and Income Assistance. BC Employment and Assistance Rate Tables — Disability Assistance — Effective 1 January 2005. <http://www.eia.gov.bc.ca/mhr/da.htm>.

<sup>362</sup> Government of Ontario, Ministry of Community and Social Services. ODSP Handbook. [http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP\\_handbook.htm](http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm).

<sup>363</sup> Government of Quebec, Emploi et Solidarité sociale. Basic Benefit. [http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base\\_en.asp](http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base_en.asp).

<sup>364</sup> Government of British Columbia, Ministry of Employment and Income Assistance. Fact Sheet — Earnings Exemption for Persons With Disabilities. [http://www.eia.gov.bc.ca/factsheets/2004/PWD\\_EarningsExemption.htm](http://www.eia.gov.bc.ca/factsheets/2004/PWD_EarningsExemption.htm).

<sup>365</sup> Government of Ontario, Ministry of Community and Social Services. ODSP Handbook. [http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP\\_handbook.htm](http://www.cfcs.gov.on.ca/CFCS/en/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm).

<sup>366</sup> Government of Quebec, Emploi et Solidarité sociale. Basic Benefit. [http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base\\_en.asp](http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base_en.asp).

Those who seek to return to work may be dissuaded by policies that would result in varying amounts of earned income being deducted from their benefit cheques, a loss of specific benefits (i.e., medical or drug benefits) or a loss of benefits altogether.

Joan Edwards-Karmazyn, Manager, Consumers Health Awareness Network Newfoundland and Labrador (CHANNAL), summed up the dilemma faced by persons living with mental illness who rely on social assistance programs, saying:

*The members of CHANNAL expressed a need for more affordable housing; fewer barriers to receiving educational and vocational services; and increased wage earning allowances while receiving social income supports.*

*Members state that they are caught in the system due to the need...for medication allowances. Therefore, one is hesitant to stop income allowances as stopping income allowances has a direct impact on also having medication benefits stopped. People are afraid to come off their benefits because the income they would make out in the real work world would not allow them to afford the \$1,500 a month for medication alone.<sup>367</sup>*

Therefore, the Committee recommends:

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| 36 | <p><b>That benefit levels and earning exemption amounts for social assistance programs for persons living with a mental illness be increased to reduce financial hardship and increase the incentive to work.</b></p> <p><b>That recipients of supplementary aid, such as help with the costs of medication, continue to be eligible for assistance for an extended period of time even if their incomes increase to levels where they are no longer eligible for financial aid for shelter or other living expenses.</b></p> |
|----|---|

#### 8.5.4 Federal Income Security Programs<sup>368</sup>

The federal government has two income support programs that may be of assistance to persons living with a mental illness: the Disability Benefit provided by the Canada Pension Plan, and sickness benefits provided by Employment Insurance. Tax assistance is available through the Disability Tax Credit.

<sup>367</sup> 14 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>368</sup> This section is drawn largely from: Standing Senate Committee on Social Affairs, Science and Technology. (November 2004) Report 1 — Mental Health, Mental Illness and Addiction: Overview of Policies and Programs in Canada, Chapter 6, pp. 118-120.

#### 8.5.4.1 Canada Pension Plan (Disability) Program (CPP(D))

The Canada Pension Plan (Disability) program is the largest single disability income program in Canada. It is generally the “first payer” of disability benefits, preceding other entities such as provincial workers’ compensation boards and private insurance companies.

CPP(D) benefits are paid to contributors under age 65 who have a physical or mental disability that is “severe and prolonged” (lasting at least one year and preventing work on a regular basis) and who meet specific requirements relating to the level of earnings and years of contribution (contributions must have been paid in four out of the previous six years). Between 1980 and 2000, the proportion of individuals receiving CPP(D) benefits attributable to mental disorders increased sharply — from 11% to 23%. Mental illness ranked second, behind disease of the musculoskeletal system, and affected a higher proportion of females than males. In 2000, mental disorders also represented the most prominent cause of CPP(D) disability among younger beneficiaries.

For many years, individuals with mental illness and addiction and their representatives have raised concerns that CPP(D) does not address the question of mental illness and disability appropriately. For example:

- Many individuals with mental illness have limited work histories. Because mental illness often strikes in early adulthood at a time when education, job skills and careers are being developed, many of these individuals are not eligible for CPP(D) due to their having insufficient years of employment. Out of necessity, many turn to provincial social assistance programs for support.
- To qualify for CPP(D) disability benefits, the beneficiary must accept the designation of having a “severe and prolonged” disability that means they cannot pursue any gainful employment on a regular basis. Because of the cyclical and unpredictable nature of mental disorders, many individuals with mental illness can work, but often only on a part-time basis; they are not necessarily capable of achieving full financial independence. In this vein, Jason Turcotte, of the Canadian Mental Health Association Office in Portage La Prairie, a member of the Partnership for Consumer Empowerment, told the Committee that “the all-or-nothing approach must be eliminated. To provide benefits only to someone while they are 100-per-cent disabled is discriminating, disempowering, and a disincentive to recovery.”<sup>369</sup> Individuals with mental illness and addiction have recommended

**To provide benefits only to someone while they are 100-per-cent disabled is discriminating, disempowering, and a disincentive to recovery.**

— Jason Turcotte

**Since disability is currently equated with permanent unemployment, individuals on CPP(D) are reluctant to look for or take employment for fear of losing their benefits.**

<sup>369</sup> 31 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/16eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

that CPP(D) pay partial or reduced benefits rather than full benefits to enable them to work part-time and still retain a portion of their benefits.

- Since disability is currently equated with permanent unemployability, individuals on CPP(D) are reluctant to look for or take employment for fear of losing their benefits. Those affected are penalized for trying to improve their circumstances even if they are not capable of participating in regular full-time work again.
- Just over half of all initial applications to CPP(D) are denied; almost two-thirds of those rejected do not apply for reconsideration. It has been suggested that the proportion of applications rejected from those with mental illness is much higher. Some claim that the system is designed in such a way as to discourage individuals from pursuing rightful claims. This is particularly true for individuals with mental disorders who, because of their illness, may lack the ability to “push the system.”

**Just over half of all initial applications to CPP(D) are denied.**

**Once qualified for CPP(D), individuals are often reluctant to make any attempt to return to work or engage in other activities that could bring their declared impaired health status into question.**

Once qualified for CPP(D), individuals are often reluctant to make any attempt to return to work or engage in other activities that could bring their declared impaired health status into question. Many fear that to do so risks triggering a reassessment of their CPP(D) eligibility, and raises the potential of a loss of income support. According to one individual living with mental illness:

CPP-Disability puts individuals in a position of having to paint themselves in the worst possible light, and define themselves in the most negative way, just to convince the worker they actually require assistance. The entire process is based on pathology rather than recovery.<sup>370</sup>

An additional concern is that CPP(D) may also inadvertently contribute to the process by which persons living with mental illness come to be viewed as permanently unemployable. Private insurance companies, in an effort to reduce their financial liability, often require their clients to apply for CPP(D) because of its “first payer” status. However, moving from employer-sponsored private insurance coverage to CPP(D) may further distance the individual from his or her employer, making a return to work more difficult.

Some progress has been made in addressing a number of these issues in recent years. For example, an allowable earnings provision gives recipients the flexibility of earning up to \$4,100 a year while remaining on CPP(D) benefits. Greater personalized contact with applicants means that clients receive telephone calls during the decision-making process to

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<sup>370</sup> Canadian Mental Health Association. (27 November 2001) Position Paper on Federal Income Security Programs, submitted to the House of Commons Subcommittee on the Status of Persons With Disabilities. <http://www.disabilitytax.ca/subs/cmha-e.pdf>.

discuss individualized needs and provide appropriate information about programs and services.

As well, a legislative change to the CPP was made in 2005 allowing for the automatic reinstatement of CPP(D) benefits. This provision allows beneficiaries who are able to return to employment to try working without fear of losing their CPP(D) benefits. If their disability recurs within a two year period, these clients are quickly returned to benefits. Cecilia Muir, Director General, Office of Disability Issues, Social Development Canada, explained to the Committee the significance of this modifications to CPP(D):

*I acknowledge it is not a whole solution, but this is a huge step forward. This feature allows a person for up to five years not to have to go back through a reapplication and all the process that one would normally need to go through. ... The projections were that at least 300 persons a year would be able to benefit. Those are individual people.<sup>371</sup>*

Finally, to make people more aware that CPP(D) supports clients in their efforts to return to work without risking a loss of benefits, the program has implemented a communication strategy. Communication tools include an annual “Staying in Touch” newsletter, website and annual correspondence to clients outlining CPP(D) return to work provisions. In addition, clients who are most likely to benefit from automatic reinstatement, in particular those with episodic disabilities, receive letters explaining how the new provision works.

In its 2003 report, the House of Commons Standing Committee on Human Resources Development and the Status of Persons with Disabilities recognized that CPP(D) does not address the question of mental illness and disability appropriately. The Committee made a number of recommendations to ensure that CPP(D) takes into account the cyclical and unpredictable nature of mental illnesses. In addition, it recommended that the federal government develop, in consultation with stakeholders and health care professionals, specific evaluation tools for these particular disabilities to be used in assessing eligibility for CPP(D).

In its response to the House of Commons committee’s report, the federal government indicated that CPP(D) guidelines already recognize recurrent and episodic disabilities, including mental disorders, and that many individuals with mental disorders currently receive CPP(D) benefits. Furthermore, it stated:

The Government therefore does not believe regulations and guidelines need to be changed to accommodate the needs of individuals with episodic or recurring conditions. Because the determination of disability for CPP is based on the functional limitations that prevent a person from working, and not simply on a medical diagnosis or prognosis, the adjudication process is able to take into consideration the short- and long-term impacts of recurrent

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<sup>371</sup> [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

or episodic medical conditions on the client's ability to function in the workplace.<sup>372</sup>

The Committee strongly rejects this view, and it recommends:

37 That the eligibility criteria for Canada Pension Plan — Disability (CPP-D) benefits be modified so that persons living with a mental illness are no longer required to demonstrate that their illnesses are severe and prolonged, but only that their illness has been diagnosed and that they are unemployable and need income support.

That the Government of Canada review how to coordinate better Employment Insurance (EI) sickness benefits and CPP-D, and examine how to eliminate structural barriers (i.e., financial disincentives) that limit opportunities to return to work.

That the Government of Canada grant authority to the CPP to permit it to sponsor research on, and the testing of, new approaches that could target people with episodic disabilities, particularly episodic mental illness.

That the Government of Canada explore ways to provide incentives to employers who hire persons living with mental illness, including the possibility of offering them CPP premium “holidays”.

#### *8.5.4.2 Employment Insurance (EI)*

Individuals with mental illness may also be eligible to receive EI benefits as a source of temporary income replacement. Some concerns have been raised, however, with respect to EI:

- In terms of EI eligibility, employees who are dismissed because of “misconduct” or quit “without just cause” are not eligible for EI benefits. Due to stigma, individuals with mental illness in the workplace often conceal their illness. When they experience difficulty on the job, they may be fired or may quit as a result of their illness, but would not be in a position to claim EI benefits because they have not previously disclosed their illness.
- When a person applies for EI sickness benefits, he/she is required to obtain a medical certificate indicating how long the illness is expected to last. The unpredictable nature of mental illness makes it difficult to provide this kind of medical information.

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<sup>372</sup> Human Resources Development Canada. (November 2003) Government of Canada's Response to “Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program,” p. 22.

- Individuals with mental illness and addiction share the view that EI should exempt individuals with recurring illnesses or disabilities from fulfilling the additional number of insurable hours required of those who are considered new to the labour force. In their view, without this exemption, individuals with mental illness are unjustly disadvantaged. Few are able to meet the eligibility criteria in terms of the total number of insurable hours required of new workers.

In his brief to the Committee, Dr. Sunil V. Patel, then President of the Canadian Medical Association, recommended that the federal government review CPP(D) and other federal income support policies to ensure that mental illness is on a par with other chronic diseases and disabilities in terms of the benefits available to affected persons.

The Committee is of the view that the criteria for EI sickness benefits should be modified so that persons living with a mental illness can qualify more easily for EI. Given the enormity of the surplus in the EI Account,<sup>373</sup> this change would not represent an undue burden on the public purse.

Therefore, the Committee recommends:

38	<b>That Employment Insurance (EI) sickness benefits be modified so that persons living with a mental illness can qualify more easily. Specifically, for persons living with a mental illness, the number of hours to be worked since the last claim should be reduced.</b>
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#### ***8.5.4.3 Disability Tax Credit (DTC)***

The Disability Tax Credit<sup>374</sup> is a non-refundable tax credit that can be used by persons with disabilities to reduce the amount of income tax they have to pay. A person can transfer the credit to his or her spouse, or to another supporting person. It is intended to help persons with disabilities bear the additional costs of living and working generated by their disability. The basic credit is worth \$1,037.76 per year.

Qualifying for the DTC is not an easy task. In order to be successful, a person must have a severe and prolonged (i.e., minimum of one year) impairment that markedly restricts his or her ability to perform a basic activity of daily living. The definition of “basic activity of daily living” is highly restrictive, and does not include working, housekeeping, recreational or

<sup>373</sup> In her November 2004 Report, the Auditor General indicated that the accumulated surplus in the EI Account had risen to \$46 billion. See: Office of the Auditor General of Canada, November 2004 Report, Chapter 8. <http://www.oag-bvg.gc.ca/domino/reports.nsf/html/20041108ce.html#ch8hd3b>.

<sup>374</sup> For a more detailed explanation of the Disability Tax Credit, see: Canada Revenue Agency, Disability amount. <http://www.cra-arc.gc.ca/agency/resourcekit/individuals/benefits-dtc-e.html>.

social activities.<sup>375</sup> Also, the amount of tax relief is small. Therefore, the Committee recommends:

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| 39 | That the eligibility criteria for the Disability Tax Credit (DTC) be modified so that persons living with a mental illness can qualify more easily, and that the amount of the DTC be increased. |
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<sup>375</sup> “Basic activity of daily living” means one of the following: perceiving, thinking, and remembering, feeding, dressing, speaking so as to be understood by a person familiar to you in a quiet setting, hearing so as to understand a person familiar to you in a quiet setting, eliminating (bowel or bladder functions), walking.

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## **PARTIE III**

### **Organisation et prestation des services**



## CHAPITRE 5: VERS UN RÉSEAU DE SERVICES TRANSFORMÉ

### 5.1 CONSENSUS SUR L'ORIENTATION DE LA RÉFORME DES SOINS DE SANTÉ MENTALE

Le chapitre 3 du présent rapport décrit la vision sous-jacente du Comité quant à l'organisation d'un système de santé mentale transformé. Cette vision s'articule autour d'un ensemble de soins intégrés, principalement communautaires et axés sur le rétablissement.

**Cette vision s'articule autour d'un ensemble de soins intégrés, principalement communautaires et axés sur le rétablissement.**

Au cours de ses audiences, le Comité a appris avec plaisir que cette vision reflète un fort consensus national sur les grandes lignes d'un système de santé mentale transformé. Le fait qu'un si grand nombre d'intervenants clés, tant des fournisseurs de services que des clients, s'entendent sur la question offre un solide tremplin à partir duquel il est possible de poursuivre la transformation de l'organisation et de la prestation des services de santé mentale<sup>147</sup>.

Il y a déjà un certain temps que des provinces se sont fixé comme objectif l'établissement d'une gamme de soins intégrés, communautaires, axés sur le rétablissement et accordant la priorité aux personnes vivant avec une maladie mentale. Par exemple, en octobre 1988, le gouvernement du Nouveau-Brunswick a créé une commission de la santé mentale ayant pour mandat de réformer la prestation des soins de cette nature. La commission a mené à bien cette tâche en 1996 en créant un réseau provincial de services de santé mentale inspiré d'une vision qui concorde bien avec celle du Comité.

**Les trois éléments clés d'un système de santé mentale transformé : le système doit être axé sur la personne et le rétablissement; il doit offrir surtout des services communautaires; il doit être intégré dans la gamme complète de soins et adapté à tous les groupes d'âge.**

Le tableau 5.1 présente de brefs extraits de documents produits au cours des dernières années qui mettent en évidence la recherche d'une approche semblable à l'égard de la réforme des services de santé mentale partout au pays. Ces extraits traitent de trois éléments clés d'un système de santé mentale transformé : le

<sup>147</sup> Comme il est précisé au chapitre 3, le Comité n'a pu consacrer aux questions touchant la consommation d'alcool et de drogues autant d'attention qu'il le prévoyait quand il a entrepris son étude de la santé mentale, des maladies mentales et de la toxicomanie. Il est conscient qu'au cours des dernières décennies, les services de santé mentale et les services de traitement de la toxicomanie étaient administrés séparément; ils ont élaboré des principes de traitement divergents, utilisé une terminologie différente et développé des cultures distinctes et souvent incompatibles. Les limites du rapport sur les questions touchant la toxicomanie signifient que le Comité n'a pas été en mesure d'examiner pleinement les ressemblances et les différences des méthodes employées par le secteur de la santé mentale et par celui du traitement de la toxicomanie. Bien que certains exemples soient tirés de ce dernier, le présent chapitre porte principalement sur la transformation de l'organisation et de la prestation des services de santé mentale. Manifestement, il ne faut pas que le Comité présume que les conclusions auxquelles il est arrivé après avoir examiné avec attention les données probantes sur la santé mentale s'appliquent nécessairement aux problèmes liés à la consommation. Certaines peuvent convenir, mais le Comité s'est efforcé d'éviter toute supposition non justifiée à cet égard.

système doit être axé sur la personne et le rétablissement; il doit offrir surtout des services communautaires; il doit être intégré dans la gamme complète de soins et adapté à tous les groupes d'âge. La dernière rangée du tableau contient des extraits d'un document publié récemment en Colombie-Britannique qui porte sur la transformation des services pour traiter les problèmes liés à la consommation et à la toxicomanie et qui dégage les trois mêmes éléments clés.

Le consensus en matière de politique présenté dans la partie 5.1 repose sur des données probantes et uniformes recueillies au Canada et à l'étranger selon lesquelles les personnes aux prises avec la maladie mentale bénéficient grandement d'une prestation accrue de services dans la collectivité. Il indique également que les systèmes reposant sur ce genre de services ne sont pas plus coûteux que les systèmes faisant surtout appel aux établissements pour la prestation de services de santé mentale. Un document publié récemment par l'Organisation mondiale de la santé (OMS) précise que «le coût des services communautaires de santé mentale est généralement le même que celui des services en établissement qu'ils remplacent»<sup>148</sup>.

Aujourd'hui, il est généralement admis que les personnes souffrant de maladie mentale peuvent mener des vies productives et satisfaisantes dans la collectivité. Certes, les personnes aux prises avec une grave maladie mentale peuvent recevoir par intermittence des soins en établissement, mais il faut instaurer des politiques afin de mettre en place les conditions voulues pour aider le plus de personnes possible à vivre dans leur collectivité.

**Les systèmes faisant surtout appel aux établissements pour la prestation de services de santé mentale.**

**Les personnes souffrant de maladie mentale peuvent mener des vies productives et satisfaisantes dans la collectivité.**

Comme Elliot Goldner l'a fait remarquer en résumant les résultats de diverses études sur la santé mentale financées grâce au Fonds pour l'adaptation des services de santé :

Jusqu'à tout récemment, l'hospitalisation à cause d'une psychose était considérée comme l'option la plus sûre, à la fois pour le patient et pour la société. Soigner les patients psychotiques à domicile était jugé trop risqué. Toutefois, l'étude portant sur le programme de traitement à domicile des cas de psychose aiguë, réalisée à Victoria, abonde dans le même sens que des recherches précédentes (c.-à-d. Wasylenki, Gehrs, Goering et Toner, 1997), selon lesquelles ces patients pouvaient être suivis en toute sécurité et stabilisés, avant de devenir à nouveau fonctionnels à un niveau raisonnable sans avoir à subir le stress perturbant de l'admission dans une unité psychiatrique<sup>149</sup>.

<sup>148</sup> Réseau des bases factuelles en santé, Organisation mondiale de la santé, (août 2003), *What Are the Arguments for Community-Based Mental Health Care?*, p. 4.

<sup>149</sup> E. Goldner, (2002), *La santé mentale*, Série de rapports de synthèse, Santé Canada, p. 8.

**Tableau 5.1 Extraits de documents provinciaux**

	<i>Services axés sur le rétablissement/ sur la personne</i>	<i>Services communautaires</i>	<i>Gamme de soins intégrés</i>
T.-N.	<p>2001<sup>150</sup></p> <p>Services axés sur la personne et sur la participation :</p> <ul style="list-style-type: none"> <li>Le système répond aux besoins particuliers des clients de tous les groupes d'âge.</li> <li>Les personnes et les collectivités définissent leurs propres besoins et participent à la planification et à la prestation des services.</li> </ul>	<p>Un [système] reposant sur des services communautaires :</p> <ul style="list-style-type: none"> <li>favorise la vie du client dans la collectivité;</li> <li>offre à proximité du domicile des soins limitant le moins possible la liberté du client.</li> </ul>	<p>Une gamme complète :</p> <ul style="list-style-type: none"> <li>propose des services tels que des mesures de soutien informelles axées sur le bien-être et le rétablissement;</li> <li>englobe la promotion, la prévention, l'intervention en situation de crise, les soins actifs, les soins continus, la gestion de cas et le soutien.</li> </ul>
	<p>2005<sup>151</sup></p> <p>La personne et la famille qui reçoivent des services doivent être l'élément central de toute intervention. La connaissance des clients, le savoir-faire et le leadership sont des éléments clés du système de santé mentale et d'aide aux toxicomanes.</p>	<p>Les approches à adopter comprennent :</p> <ul style="list-style-type: none"> <li>l'établissement dans chaque région d'un ensemble de services communautaires spécialisés en santé mentale et en aide aux toxicomanes répondant le mieux aux besoins de la population et fondé sur des pratiques exemplaire.</li> </ul>	<p>La nature de la maladie mentale et de la toxicomanie exige souvent une approche globale multidisciplinaire qui comporte l'accès à divers programmes de traitement et de soutien. Aucun service ne peut généralement répondre à lui seul aux besoins variés de cette population. La coopération et la collaboration au sein d'un ensemble de fournisseurs de services sont essentielles.</p>
Qc	<p>2005<sup>152</sup></p> <p>Le rétablissement : Le plan d'action réaffirme la capacité des personnes de prendre le contrôle de leur vie et de participer activement à la vie en société.</p> <p>Le rétablissement nous invite à soutenir les personnes atteintes d'un trouble mental en les aidant à réintégrer leur rôle en société, malgré l'existence chez elles de symptômes ou de</p>	<p>Le réseau de la santé mentale doit offrir des services de qualité à l'ensemble de la population (enfants, jeunes, adultes, communautés culturelles, autochtones, etc.). Pour favoriser cette vision, les mesures du plan visent en priorité la mise en place de services de première ligne dans les communautés locales en mettant à profit</p>	<p>La continuité : Le plan d'action met l'accent sur la nécessité de répondre aux besoins des personnes en assouplissant les frontières qui balisent nos interventions et en assurant les liaisons nécessaires afin de réduire les ruptures dans la continuité des services.</p>

<sup>150</sup> Gouvernement de Terre-Neuve-et-Labrador, (septembre 2001), Valuing Mental Health: A Framework to Support the Development of a Provincial Mental Health Policy for Newfoundland and Labrador.

<sup>151</sup> Gouvernement de Terre-Neuve-et-Labrador, (2005), Working Together for Mental Health: A Provincial Policy Framework for Mental Health & Addictions Services in Newfoundland and Labrador.

<sup>152</sup> Gouvernement du Québec, ministère de la Santé et des Services sociaux, (2005), *Plan d'action en santé mentale 2005-2010* — La force des liens.

	<i>Services axés sur le rétablissement/ sur la personne</i>	<i>Services communautaires</i>	<i>Gamme de soins intégrés</i>
	handicaps, car c'est généralement par l'interaction sociale qu'une personne apprend que ses efforts lui donnent du pouvoir sur son environnement.	l'expertise des intervenants qui y travaillent. Une organisation favorisant un passage fluide vers les services spécialisés est à la base de ce plan.	
Ont.	1999 <sup>153</sup>  Le client est l'élément central du système de santé mentale.	Les personnes aux prises avec de graves troubles mentaux pourront acquérir une plus grande autonomie, c'est-à-dire qu'elles pourront vivre dans la collectivité sans être soumises à une trop grande intervention de la part des services officiels et qu'elles pourront, dans la mesure du possible, prendre leurs propres décisions.	Les services de santé mentale : <ul style="list-style-type: none"> <li>▪ sont fournis dans le cadre d'un ensemble complet mis au point pour répondre aux besoins des clients et fondé sur des pratiques exemplaires.</li> </ul>
	2002 <sup>154</sup>  Un facteur de réussite essentiel de la réforme des services de santé mentale est le respect du principe selon lequel le rétablissement — défini par la personne et non par les fournisseurs de services — est possible pour toutes les personnes souffrant de maladie mentale. Si le traitement et le soutien appropriés sont offerts, ces personnes peuvent prendre leur vie en main, avoir de nouveaux objectifs et des aspirations et jouer un rôle actif au sein de la société.  Le Forum provincial croit que le principe du rétablissement doit être accepté et adopté comme faisant partie intégrante d'une réforme du système de santé mentale.	Un régime qui crée des systèmes locaux de soins auprès desquels les personnes atteintes de maladie mentale ainsi que leur famille et leur réseau de soutien peuvent obtenir une gamme de services communautaires adaptés à leurs besoins.  L'idée selon laquelle les services de santé mentale doivent être mis au point au sein d'une collectivité et non reproduits par le système de santé mentale est au cœur du principe de rétablissement. La collectivité devrait permettre aux personnes souffrant de maladie mentale de se trouver un emploi rémunérateur, de participer à des programmes d'aide aux études, de faire du bénévolat et de participer à la société de façon constructive.	Un système qui dispense sans faute une gamme complète de soins grâce à des programmes, à des services et à des mesures de soutien offerts à toutes les étapes de la vie et aussi près de chez la personne que possible.

<sup>153</sup> Gouvernement de l'Ontario, (1999), *Franchir les étapes : Cadre de prestation des services de santé mentale et des services de soutien connexes*.

<sup>154</sup> Gouvernement de l'Ontario, (décembre 2002), *The Time Is Now: Themes and Recommendations for Mental Health Reform in Ontario*. Rapport final du Forum provincial des présidents de groupes d'étude sur la mise en œuvre de la réforme des services de santé mentale.

	<i>Services axés sur le rétablissement/ sur la personne</i>	<i>Services communautaires</i>	<i>Gamme de soins intégrés</i>
Alb. 2004 <sup>155</sup>	Les clients et leur famille passeront avant tout. L'objectif premier des services, plans, recherches et mesures de soutien en santé mentale est d'améliorer le sort des personnes aux prises avec la maladie mentale et celui de leur famille. Cela implique que les services soient adaptés à la situation des clients et que ceux-ci soient traités dans la dignité et le respect. Cela signifie surtout que les personnes souffrant de maladie mentale et de toxicomanie peuvent avoir une vie productive et satisfaisante.	Tous les Albertains doivent avoir un accès optimal aux meilleurs soins en santé mentale quel que soit l'endroit où ils habitent dans la province. Chaque client recevra le service approprié à l'endroit qui convient le mieux, que ce soit dans la collectivité, à l'hôpital ou dans un établissement spécialisé.	Plutôt que de faire partie du système fragmenté qui est offert aujourd'hui, les services de santé mentale seront pleinement intégrés au système de santé; l'importance de la santé mentale sera reconnue et celle-ci aura sa place dans le système de soins de santé. Des régimes de soins seront en place de sorte que les personnes souffrant de maladie mentale auront accès à des soins continus dispensés par divers fournisseurs de services et à du soutien offert par un éventail de fournisseurs de soins de santé, des responsables de la santé, des organismes communautaires et des ministères provinciaux.
C.-B. 2004 <sup>156</sup>	L'expression « axé sur le client » renvoie aux besoins, aux forces, aux motivations et aux objectifs de chaque personne. Les interventions axées sur le client ont lieu là où il se trouve; elles suppriment les obstacles à l'accès et respectent la disposition du client à changer. Compte tenu de la comorbidité de la toxicomanie et des troubles mentaux, l'expression « axé sur le client » renvoie également à un système intégré de services de santé mentale et de traitement de la toxicomanie fondé sur des données probantes.	Un autre élément d'une intervention efficace consiste à permettre à des gens et à des groupes de la collectivité de participer activement aux efforts pour venir à bout d'une consommation abusive plutôt que d'en être la cible passive. Les organismes communautaires offrent un appui essentiel en tendant la main aux personnes faisant partie des groupes les plus vulnérables à une consommation abusive, en favorisant l'inclusion sociale, en appuyant les clients et leur famille et en assurant un lien essentiel au transfert du savoir.	L'intégration du système peut minimiser la fragmentation qui fait en sorte que des gens passent à travers les mailles du filet. Une intervention efficace dans les cas de troubles concomitants et de diagnostics multiples exige une gamme de services intégrés de santé mentale et de traitement de la toxicomanie qui est fondée sur des données probantes. Ces services comprennent la promotion de la santé, la prévention, la réduction des méfaits, le dépistage précoce, le traitement, la réadaptation à long terme et la prévention des rechutes, la réintégration dans la collectivité et le soutien communautaire.

<sup>155</sup> Gouvernement de l'Alberta, (avril 2004), *Advancing the Mental Health Agenda: A Provincial Mental Health Plan for Alberta*.

<sup>156</sup> Gouvernement de la Colombie-Britannique, ministère de la Santé, (2004) Every Door is the Right Door: A British Columbia Planning Framework to Address Problematic Substance Use and Addiction.

En fait, bien des gens obtiennent de meilleurs résultats lorsque des services adéquats sont dispensés dans la collectivité. Un rapport publié récemment par la Community Mental Health Evaluation Initiative (CMHEI) en Ontario arrivait à la conclusion suivante :

Les résultats des projets de la CMHEI démontrent clairement que les services communautaires de santé mentale ont des effets positifs sur la vie des personnes atteintes de maladies mentales graves et sur celle de leur famille et des personnes qui s'occupent d'elles. Les données recueillies indiquent que les services communautaires contribuent à diminuer les symptômes de maladies mentales graves et à accroître la capacité des personnes qui en souffrent à vivre dans la collectivité plutôt qu'à l'hôpital ou en établissement. De nombreux clients montrent des signes d'amélioration dans leur vie de tous les jours et sur le plan du comportement dans la collectivité, des symptômes et de l'abus d'alcool et de drogues. Ils ont aussi moins de crises et passent moins de jours à l'hôpital<sup>157</sup>.

Même si le Comité croit qu'un système remanié doit être fondé avant tout sur la collectivité, les services en établissement sont aussi un élément essentiel d'une gamme de soins. C'est le recours excessif à certains services en établissement qui pose problème depuis longtemps. Il faut trouver la combinaison adéquate de soins en établissement et de services communautaires. À cet égard, le Comité approuve l'approche présentée dans le document susmentionné de l'OMS :

**Un système remanié doit être fondé avant tout sur la collectivité, les services en établissement sont aussi un élément essentiel d'une gamme de soins. C'est le recours excessif à certains services en établissement qui pose problème depuis longtemps.**

Au cours des vingt dernières années, un débat s'est engagé entre les tenants des services de santé mentale dans les hôpitaux et les partisans des services de santé mentale dispensés principalement, voire exclusivement, dans la collectivité. Une troisième solution consiste à offrir à la fois des services communautaires et des soins en établissement. Ce modèle de soins équilibré met l'accent sur la prestation de services dans le milieu communautaire habituel à proximité de la population desservie, et prévoit des séjours à l'hôpital aussi brefs que possible, organisés rapidement et uniquement si nécessaire. Plutôt que de chercher à savoir qui des soins hospitaliers et des soins communautaires sont les meilleurs, cette interprétation équilibrée des services communautaires favorise l'examen de la meilleure combinaison d'approches pour une région donnée et à une certaine période<sup>158</sup>.

<sup>157</sup> Community Mental Health Evaluation Initiative (CMHEI), (octobre 2004), *Making a Difference: Ontario's Community Mental Health Evaluation Initiative*, p. 43.

<sup>158</sup> Réseau de bases factuelles en santé, Organisation mondiale de la Santé, (août 2003), *What Are the Arguments for Community-Based Mental Health Care?* p. 5.

Beaucoup de services dont les gens ont besoin pour bien vivre dans leur collectivité peuvent provenir d'établissements tels que les hôpitaux. L'enjeu principal consiste à faire en sorte que ces services soient accessibles dans la collectivité et que les personnes qui en ont besoin ne soient pas hospitalisées inutilement. Les services communautaires doivent être accessibles, appropriés et dispensés au bon endroit et au bon moment, et comporter le moins de restrictions possible tout en donnant de bons résultats cliniques. Beaucoup d'hôpitaux mettent en œuvre d'excellents programmes communautaires qui remplissent ces critères.

De plus, il importe que le plus grand nombre possible de fournisseurs de services et d'intervenants unissent leurs forces pour atteindre un but commun. Même s'il faut accorder de l'importance aux ressources hospitalières et continuer de les offrir, le processus de réforme devrait donner lieu à une réorientation de tous les services qui favorise la vie dans la collectivité et évite l'hospitalisation.

**Les services communautaires doivent être accessibles, appropriés et dispensés au bon endroit et au bon moment, et comporter le moins de restrictions possible tout en donnant de bons résultats cliniques. Beaucoup d'hôpitaux mettent en œuvre d'excellents programmes communautaires qui remplissent ces critères.**

## 5.2 CERTAINS AVANTAGES DES SERVICES COMMUNAUTAIRES

### 5.2.1 De nombreux services communautaires permettent de réaliser des économies

Comme il a déjà été mentionné, l'information recueillie indique que « le coût des modèles de soins communautaires est essentiellement le même que celui des services qu'ils remplacent; ces modèles ne peuvent donc être considérés avant tout comme des mesures d'économie ou de compression de coûts »<sup>159</sup>. Par ailleurs, un système communautaire n'a pas à être plus onéreux que des soins en établissement. En fait, de nombreux services sont offerts à moindre coût dans la collectivité qu'à l'hôpital<sup>160</sup>.

Prenons un exemple<sup>161</sup>. Il y a cinq ans, un programme de logement supervisé a accueilli 30 personnes parmi les plus gravement handicapées de l'Ontario. Ces personnes avaient entre 41 et 69 ans et étaient malades depuis 27 ans en moyenne. Elles souffraient toutes d'une grave maladie mentale et de divers autres troubles médicaux :

- 9 d'entre elles étaient diabétiques;
- 8 avaient des antécédents de consommation d'alcool ou de drogues;
- 6 accusaient un retard de développement;

<sup>159</sup> *Ibid.*, p. 15.

<sup>160</sup> Fédération des programmes communautaires de santé mentale et de traitement des toxicomanies de l'Ontario, (2003), *Outcomes and Effectiveness: The Success of Community Mental Health and Addiction Programs*, p. 8-9.

<sup>161</sup> Fédération des programmes communautaires de santé mentale et de traitement des toxicomanies de l'Ontario, (2004), *The Benefits of Funding Addiction and Mental Health Services*, p. 7-8.

- 6 avaient dû être internées sur recommandation de la Commission ontarienne d'examen;
- 5 souffraient d'arthrite;
- 3 avaient une maladie pulmonaire obstructive chronique;
- 3 avaient des troubles épileptiques;
- 1 était atteinte d'un cancer.

Avant de participer au programme, tous les résidents avaient reçu des soins de longue durée dans des hôpitaux psychiatriques de la province; beaucoup avaient essayé à plusieurs reprises de fonctionner dans des logements autres qu'une chambre en établissement, mais en avaient été incapables.

Dans le logement, le programme offre les services de soutien nécessaires pour que les résidents composent avec leur maladie mentale. Un autre fournisseur de services s'occupe des besoins médicaux des résidents.

Malgré la gravité de leur état, les résidents ont remarquablement bien réussi à s'adapter à leur milieu grâce au programme. Ils ont développé un sentiment d'appartenance; ils se soutiennent les uns les autres et ils atteignent des objectifs qu'ils auraient été incapables d'atteindre auparavant.

Depuis le début du programme, les résidents ont passé très peu de temps à l'hôpital, ce qui a permis au système de santé de réaliser des économies de 4,4 millions de dollars par année (soit 146 000 \$ par résident). Cette estimation est établie à partir du nombre de jours que chaque résident aurait passé à l'hôpital s'il n'avait pas emménagé dans un logement supervisé, multiplié par le taux journalier d'hospitalisation, moins le coût actuel du programme de logement.

L'économie que présente cet exemple n'est pas exceptionnelle. En Ontario, par exemple, 3 130 clients qui ont fait l'objet d'un suivi intensif dans la communauté (SIC) en 2003-2004 ont passé en moyenne 26 jours à l'hôpital comparativement à 77 jours l'année précédente, soit une réduction de 87 p. cent. En 2003-2004, 66 p. cent des clients du SIC en Ontario n'ont pas été admis à l'hôpital. On estime que le SIC a permis de réaliser des économies de 82 millions de dollars en 2002-2003 et de 77,6 millions de dollars en 2003-2004<sup>162</sup>.

Par ailleurs :

- Steve Lurie, directeur exécutif, Association canadienne pour la santé mentale (ACSM) du Grand Toronto, a mentionné une baisse de l'ensemble des coûts d'hospitalisation, qui ont été ramenés de 1 358 136 \$ à 172 692 \$, pour 56 personnes qui ont bénéficié de services complets de gestion de cas;

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<sup>162</sup> Ministère de la Santé de l'Ontario, 2003-04 ACT Data Outcome Monitoring Report.

- Wendy Czarny a signalé une réduction de 89 p. cent du séjour moyen à l'hôpital des participants à un programme de logement supervisé des Waterloo Regional Homes for Mental Health<sup>163</sup>.

Les programmes axés sur le traitement de la toxicomanie dans la collectivité permettent de réaliser des économies similaires. Par exemple<sup>164</sup> :

- 89 p. cent des toxicomanes qui ont reçu un traitement dans un service communautaire de gestion du sevrage ont continué de bien y répondre six mois plus tard pour ce qui est d'une réduction considérable de la consommation et d'une augmentation de l'estime de soi et de la confiance en soi;
- sans les services communautaires de gestion du sevrage, 5 p. cent des clients possibles seraient probablement incarcérés et 11 p. cent hospitalisés;
- chaque dollar affecté à des services communautaires de traitement de l'alcoolisme permet d'économiser de 4 \$ à 12 \$ de coûts médicaux, économiques et sociaux à long terme;
- la rareté des services de gestion du sevrage dans la collectivité oblige beaucoup de personnes à se tourner vers les salles d'urgence des hôpitaux pour obtenir des services. En effet, des recherches laissent entrevoir, selon une estimation très prudente, qu'entre 10 et 30 p. cent de toutes les visites à l'urgence sont dues à des problèmes liés à la consommation d'alcool.

## 5.2.2 Autres avantages des services offerts dans la collectivité

Il est manifestement plus facile d'intégrer les idées de la collectivité dans un système communautaire que dans un système institutionnel, et de l'adapter aux besoins et aux valeurs de celle-ci. En implantant les services dans la collectivité dans la mesure du possible, il est aussi plus facile de demander aux responsables de l'organisation et de la prestation de ces services de rendre des comptes à la collectivité elle-même.

Le Comité croit que ces caractéristiques des systèmes communautaires permettent plus particulièrement d'adapter pleinement les soins et les services aux traditions des Autochtones du Canada. Le passage à un système communautaire favorise donc la participation des collectivités autochtones à la conception et à la mise en œuvre de programmes de santé mentale qui répondent à leurs besoins<sup>165</sup>.

**En implantant les services dans la collectivité dans la mesure du possible, il est aussi plus facile de demander aux responsables de l'organisation et de la prestation de ces services de rendre des comptes à la collectivité elle-même.**

**Le passage à un système communautaire favorise donc la participation des collectivités autochtones à la conception et à la mise en œuvre de programmes de santé mentale qui répondent à leurs besoins.**

<sup>163</sup> Les exemples sont tirés du document suivant : Fédération des programmes communautaires de santé mentale et de traitement des toxicomanies de l'Ontario, (2003), Outcomes and effectiveness: The success of community mental health and addiction programs, p. 9 et 12.

<sup>164</sup> *Ibid.*, p. 9.

Il existe en outre de nombreuses autres possibilités d'intégrer les services communautaires de manière à accorder la place centrale aux clients. Il devient plus facile d'éviter les cloisonnements en mettant l'accent sur la prestation de services communautaires quelle que soit la source de leur financement.

Enfin, le fait de dispenser des services dans la collectivité permet aux bénévoles et aux membres de la famille de jouer un rôle plus important dans l'organisation et la prestation de ces services; il est ainsi possible d'élargir la gamme des services offerts aux personnes souffrant de maladie mentale et de favoriser le rétablissement dans la mesure du possible.

### 5.3 UNE GAMME DE SOINS INTÉGRÉS

Avant de présenter des recommandations précises sur la mise en place d'une gamme de soins intégrés et principalement communautaires, il est nécessaire d'examiner de façon plus approfondie la forme que prendrait un tel système. Le rapport final du Forum provincial des présidents de groupes d'étude sur la mise en œuvre de la réforme des services de santé mentale de l'Ontario contient la description succincte suivante des effets positifs qu'une gamme de soins intégrés aurait sur la vie des personnes souffrant de maladie mentale :

**Le fait de dispenser des services dans la collectivité permet aux bénévoles et aux membres de la famille de jouer un rôle plus important dans l'organisation et la prestation de ces services.**

#### Ce qui sera différent

Les personnes ayant une déficience psychique vivent dans un logement intégré qu'elles ont choisi dans leur collectivité et occupent un emploi ou participent à des activités constructives de leur choix; elles entretiennent de bonnes relations avec leur famille; elles ont des amis qu'elles peuvent aider et sur qui elles peuvent compter.

Ces personnes ont accès à des services dans l'élaboration, la sélection et l'évaluation desquels elles ont joué un rôle déterminant. Ces services visent à les aider dans leur processus de rétablissement au sein de leur collectivité; ils sont dispensés à proximité du domicile et de la façon la moins dérangeante possible.

Ces personnes ont accès à une gamme complète, équilibrée et bien intégrée de soins communautaires, ambulatoires et hospitaliers dispensés par des professionnels et par des pairs.

Les services sont offerts dans le contexte des situations économique, culturelle et sociale des clients et y sont adaptés, ils reposent sur des connaissances pertinentes et à jour et sont axés sur l'adaptation, la prise en main personnelle, l'autodétermination et le rétablissement.

<sup>165</sup> Voir les chapitres 13 et 14 pour un examen plus approfondi des questions relatives à la santé et au bien-être des Autochtones du Canada.

Des efforts visant à modifier les attitudes négatives du public et les comportements qui en découlent, notamment la discrimination, sont déployés dans les collectivités et donnent de bons résultats. Les ressources communautaires locales et la participation de tous les citoyens à la vie de la collectivité font partie intégrante du cadre de soutien communautaire.

Les bénéficiaires des services ont les ressources et le pouvoir de tenir les fournisseurs de services et les bailleurs de fonds responsables de la qualité des services de santé mentale offerts.

Les personnes ayant une déficience psychique ne se distinguent pas par leur déficience ou leur maladie, elles sont appréciées pour leurs forces, elles ont un pouvoir de décision et mènent la vie qu'elles choisissent au mieux de leurs capacités.

Source : Gouvernement de l'Ontario, (décembre 2002), *The Time Is Now: Themes and Recommendations for Mental Health Reform in Ontario*. Rapport final du Forum provincial des présidents de groupes d'étude sur la mise en œuvre de la réforme des services de santé mentale

Les principaux genres de services qui sont nécessaires pour faire de ce système une réalité sont présentés dans le diagramme de la gamme de services, qui est tiré de l'un des rapports de l'Ontario Mental Health Implementation Task Force (celui du Toronto-Peel Implementation Task Force)<sup>166</sup>.

Ce cadre ne présente pas une liste et des catégories définitives de services; la liste n'est pas exhaustive, mais elle donne un aperçu des services nécessaires. Le modèle présenté doit donc être considéré comme un moyen pratique de décrire la gamme et les genres de services qu'il faut mettre en place dans un système de santé mentale transformé.

Le cadre a l'avantage d'englober la gamme de services et il présente trois catégories de besoins (de première ligne, intensifs et spécialisés) auxquelles s'ajoute une quatrième qui comprend des besoins communs aux autres catégories. Cette terminologie s'éloigne du vocabulaire communément employé que certains associent à une approche médicale (soins primaires, secondaires et tertiaires). Comme il est indiqué au chapitre 3, le Comité croit fermement qu'il faudrait aborder les questions relatives à la santé mentale selon diverses perspectives, le modèle médical étant une seule de celles-ci.

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**Les services de première ligne concernent la prévention, l'évaluation et le traitement par des fournisseurs de premier recours**

**Il faut donc que les clients, quels que soient leurs besoins, puissent obtenir facilement des services de première ligne.**

**Les services de première ligne doivent être liés les uns aux autres, de même qu'aux services intensifs et transversaux auxquels ils peuvent faire appel s'il y a lieu.**

<sup>166</sup> Ces rapports prennent comme point de départ le document *Making it Happen: Operational Framework for the Delivery of Mental Health Services and Supports*, publié en 1999 par le gouvernement de l'Ontario.

## Services de première ligne

Information et  
aiguillage

Prise de contact et  
engagement

Évaluation initiale et  
planification des soins

Intervention  
en situation de crise

Services d'urgence en  
milieu hospitalier

Soins de première ligne

## Services intensifs

Gestion  
intensive  
de cas

Services  
communautaires  
intensifs de traitement  
et de réadaptation

Services intensifs  
internes et externes en  
milieu hospitalier

## Services spécialisés

Équipes de suivi intensif  
dans la communauté

Services spécialisés de  
proximité

Services régionaux de  
psychiatrie légale

Traitement en  
établissement

Services spécialisés en  
établissement

Services de  
logement et de  
soutien au  
logement

Services de  
soutien  
pédagogiques et  
professionnels

Services de  
soutien  
socio-récréatifs

Groupes  
d'entraide pour  
les clients

Groupes  
d'entraide pour  
les familles

## Services transversaux

Chaque catégorie de besoins est rattachée à un ensemble particulier de services. Les clients reçoivent généralement des services dont la plupart relèvent d'une catégorie en particulier, sans toutefois s'y restreindre.

*a) Services de première ligne*

Les *services de première ligne* concernent la prévention, l'évaluation et le traitement par des fournisseurs de premier recours, notamment des médecins de famille, des cliniques offrant des soins de première ligne et des fournisseurs de services de santé mentale, de services sociaux et de services d'urgence en milieu hospitalier. La plupart des personnes aux prises avec des problèmes de santé mentale ont d'abord accès à des services de première ligne, normalement dispensés par leur médecin de famille ou une équipe de premier recours. Si la maladie n'est pas trop grave ou qu'elle est de courte durée, les services de première ligne sont généralement suffisants pour répondre aux besoins de la personne.

Il faut donc que les clients, quels que soient leurs besoins, puissent obtenir facilement des services de première ligne. Les fournisseurs de ces services doivent pouvoir répondre à des besoins très variés et être extrêmement sensibles à la confusion, à la peur et aux préoccupations des personnes qui présentent des symptômes de maladie mentale, peut-être pour la première fois. Ils doivent également tenir compte des différences culturelles de manière à répondre adéquatement aux besoins de personnes de diverses origines.

Les services de première ligne doivent être liés les uns aux autres, de même qu'aux services intensifs et transversaux auxquels ils peuvent faire appel s'il y a lieu. Les fournisseurs de services de première ligne aiguilleront généralement les personnes chez qui on diagnostique une maladie mentale grave et permanente vers des services intensifs ou spécialisés afin qu'ils reçoivent des soins complémentaires.

*b) Services intensifs*

Les *services intensifs* sont les services d'évaluation, de traitement et de soutien en santé mentale qui sont offerts au sein de la collectivité et dans le milieu hospitalier aux personnes souffrant d'une grave maladie mentale. Ces personnes ont souvent besoin de services continus à long terme, mais pas nécessairement de contacts quotidiens. Les services intensifs visent à offrir contacts et soutien continus aux personnes qui risqueraient autrement d'être placées en établissement de soins de santé ou d'être incarcérées de façon répétée ou prolongée. Des services communautaires intensifs devraient répondre aux besoins de la plupart des personnes atteintes d'une grave maladie mentale. Les personnes qui vivent une perturbation aigüe de leurs activités personnelles et qui sont très vulnérables, par

**Les services intensifs sont les services d'évaluation, de traitement et de soutien en santé mentale qui sont offerts au sein de la collectivité et dans le milieu hospitalier aux personnes souffrant d'une grave maladie mentale.**

**Les services de cette catégorie visent à traiter les maladies mentales graves et complexes les plus répandues dans la population**

exemple une femme ayant une grave dépression post-partum, pourraient également avoir besoin de ce type de services.

Les services de cette catégorie visent à traiter les maladies mentales graves et complexes les plus répandues dans la population (notamment les troubles concomitants, les troubles de l'alimentation, le premier épisode de schizophrénie et les troubles de la personnalité). La gestion intensive des cas peut faciliter l'intégration des services. Les services intensifs doivent avoir des liens solides avec les services de première ligne et les services transversaux et recevoir l'appui des services spécialisés de sorte qu'ils puissent ensemble répondre efficacement aux besoins particuliers ou très complexes de leurs clients.

### c) *Services spécialisés*

Les *services spécialisés* sont des programmes de santé mentale hautement spécialisés qui sont mis en œuvre dans la collectivité ou en milieu hospitalier et qui sont destinés aux personnes ayant une maladie mentale grave caractérisée par l'instabilité et des troubles complexes. Seules les rares personnes qui souffrent d'une maladie mentale grave et doivent avoir des rapports quotidiens en permanence avec des fournisseurs de services devront avoir accès à ce genre de services. Comme il s'agit des ressources les plus spécialisées, les moins accessibles et les plus coûteuses du système de santé mentale, ces services doivent être réservés aux personnes qui en ont vraiment besoin et dispensés uniquement lorsque les services intensifs et transversaux n'ont pas fonctionné pour une personne donnée.

**Les services spécialisés sont des programmes de santé mentale hautement spécialisés qui sont mis en œuvre dans la collectivité ou en milieu hospitalier et qui sont destinés aux personnes ayant une maladie mentale grave caractérisée par l'instabilité et des troubles complexes.**

**Soins spécialisés et soins à long terme en établissement ne sont pas synonymes.**

Les personnes suivantes ont des problèmes nécessitant des services spécialisés :

- les personnes âgées souffrant de démence, de psychose et de maladie,
- les personnes qui accusent un retard de développement accompagné de troubles psychiatriques et qui ont fréquemment des comportements agressifs,
- les personnes schizophrènes qui ont des tendances psychotiques, agressives ou suicidaires chroniques,
- les personnes ayant des troubles de l'humeur complexes et réfractaires.

Soins spécialisés et soins à long terme en établissement ne sont pas synonymes. Les services de traitement, de réadaptation et de soutien peuvent être dispensés par des équipes multidisciplinaires qui travaillent de façon à permettre à de nombreuses personnes atteintes de ces maladies de continuer à vivre dans la collectivité.

Les personnes qui reçoivent des soins spécialisés n'auront pas toujours besoin de cette catégorie de services. Il faut surveiller et réévaluer continuellement la nécessité de leur offrir la gamme complète de services à mesure qu'elles franchissent les étapes de leur rétablissement et que leurs besoins changent.

d) *Services transversaux*

Le Toronto-Peel Implementation Task Force utilise l'expression *services transversaux* pour parler des services dont une personne peut avoir besoin alors qu'elle reçoit des services de santé mentale de première ligne, intensifs ou spécialisés. Les services transversaux comprennent les services de logement et de soutien au logement, les services de soutien pédagogique et professionnel, les haltes-accueil et autres services de soutien sociaux et récréatifs, de même que les groupes d'entraide pour les clients et les familles. Les services transversaux sont normalement dispensés de façon plus efficace et efficiente dans la collectivité; ce sont les services que les personnes souffrant de maladie mentale et leur famille mentionnent le plus souvent comme étant essentiels au rétablissement.

**Les services transversaux comprennent les services de logement et de soutien au logement, les services de soutien pédagogique et professionnel, les haltes-accueil et autres services de soutien sociaux et récréatifs, de même que les groupes d'entraide pour les clients et les familles.**

### 5.3.1 Une gamme locale et complexe de services

La section précédente décrit les services devant être offerts aux personnes souffrant d'une maladie mentale pour leur permettre d'avoir des vies intéressantes et productives dans la collectivité. Dans la pratique toutefois, les services offerts dépendent de nombreux facteurs liés à l'histoire et aux conditions de chaque collectivité; chacune a un agencement de services qui lui est propre. Ces services varient non seulement d'une province à l'autre, mais également d'une région et d'une municipalité à l'autre.

**Le Comité ne croit pas qu'il soit sage d'essayer d'imposer un modèle uniforme qui serait mis en œuvre partout au pays.**

Cette inévitable variation régionale a été mentionnée dans le plan de santé mentale que le gouvernement du Québec a présenté récemment :

Les réalités territoriales, ainsi que l'expérience et l'expertise disponibles, peuvent faire en sorte que le continuum de services en santé mentale se présente de façons différentes d'un territoire local à l'autre. Ces adaptations locales sont nécessaires pour permettre un bon ajustement des services aux besoins de la population. Par ailleurs, l'existence d'un continuum de services de base (ce que nous avons appelé les « services requis ») est incontournable<sup>167</sup>.

<sup>167</sup> Ministère de la Santé et des Services sociaux du Québec, (2005), *Plan d'action en santé mentale 2005-2010* — *La force des liens*, p. 72.

Au cours de ses audiences pancanadiennes, le Comité a été impressionné par les soins communautaires intégrés offerts à Brandon (Manitoba) qu'ont décrit des témoins. Une étude plus poussée des attachés de recherche du Comité, qui ont visité Brandon au cours de l'été 2005, a confirmé la première impression du Comité : cette localité est un excellent exemple des bons résultats que peuvent donner des efforts soutenus et une planification minutieuse. Comme il est mentionné au chapitre 3, l'expérience de Brandon fait toutefois mieux comprendre à quel point les efforts visant à offrir une gamme de soins intégrés sont complexes et de nature essentiellement locale.

Le Comité ne croit pas qu'il soit sage d'essayer d'imposer un modèle uniforme qui serait mis en œuvre partout au pays. Il n'est pas non plus possible (ni souhaitable) de le faire à l'échelle provinciale parce que l'efficacité et l'efficience des services offerts dépendent dans une large mesure de certaines particularités locales, notamment l'historique des établissements locaux ainsi que le nombre de personnes vivant dans chaque collectivité et leurs particularités. Le cas de Brandon illustre ce point important. Même si cette localité ne peut servir de modèle uniforme, il est possible de tirer de précieuses leçons de sa réussite en matière d'intégration des services de santé mentale et de s'en inspirer de façon créative dans toutes les régions du pays.

Le sud-ouest du Manitoba est une région majoritairement rurale dont le principal centre urbain est Brandon, une ville de 45 000 personnes. Dans cette province, les soins de santé sont administrés par des offices régionaux de la santé (ORS). L'ORS de Brandon dessert la ville en plus d'offrir des services d'aiguillage et d'autres services à l'ORS d'Assiniboine (112 000 milles carrés, population de 80 000 personnes), de même qu'à quatre autres ORS dans des régions rurales au nord et à l'est de Brandon.

Pendant la plus grande partie du XX<sup>e</sup> siècle, les services de santé mentale offerts à la population de Brandon et de la partie ouest du Manitoba étaient dispensés par le Centre de santé mentale de Brandon (CSMB), important établissement psychiatrique fondé au début du siècle. Au cours des années 1980, les responsables de la santé mentale de Brandon ont commencé à planifier la décentralisation des services du CSMB vers la collectivité. Le nombre de lits dans les installations vieillissantes du CSMB a commencé à diminuer au cours de la période et le CSMB a fermé ses portes progressivement de 1994 à 1999.

**Nous avons dû amener les patients et le personnel à laisser de côté leurs croyances pour accepter le principe selon lequel les gens peuvent vivre avec une maladie mentale dans la collectivité.**

— **Albert Hajes**

**Les principes clés incluaient le recrutement et la formation de personnel paraprofessionnel de supervision afin d'avoir des rapports personnalisés et fréquents avec les clients et de les aider à vivre de façon indépendante.**

— **Albert Hajes**

Albert Hajes, coordonnateur régional des Programmes de santé mentale de l'Office régional de la santé de Brandon, a décrit au Comité de quelle façon se faisait la gestion des principaux aspects de cette transition<sup>168</sup>. Il fallait d'abord changer les mentalités :

<sup>168</sup> 1<sup>er</sup> juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evd-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evd-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Un point très important, c'est que, à cause de la fermeture du Centre de santé mentale de Brandon, nous avons dû amener les patients et le personnel à laisser de côté leurs croyances pour accepter le principe selon lequel les gens peuvent vivre avec une maladie mentale dans la collectivité et avoir une bonne qualité de vie, notamment en y participant davantage à titre de citoyens à part entière. Il a fallu rajuster le tir en abandonnant le modèle institutionnel traditionnel non seulement auprès du personnel et des patients, mais aussi de la collectivité en général.*

M. Hajes a aussi traité de la nécessité d'une bonne planification :

*Une transition de cette envergure n'aurait jamais été possible sans l'élaboration de solides services communautaires, au sein de la collectivité générale, et permettant de soutenir les clients. Avant d'appliquer la réforme en santé mentale et la transition des services, on a beaucoup travaillé pour renforcer la capacité de la structure de services et de la collectivité de soutenir les clients.*

Il a ensuite décrit certaines des mesures prises :

**...nous avons accordé beaucoup d'attention à l'exécution de programmes sociaux de soutien.**  
— Brent White

*Les principes clés incluaient le recrutement et la formation de personnel paraprofessionnel de supervision afin d'avoir des rapports personnalisés et fréquents avec les clients et de les aider à vivre de façon indépendante. Nous avons travaillé à renforcer les compétences et les capacités des clients pour qu'ils puissent acquérir les habiletés nécessaires pour fonctionner avec une relative autonomie. Nous avons aidé nos clients à accéder aux ressources et à participer davantage à la collectivité. Nous avons établi l'éventail complet de services dont on a besoin pour aider les clients dans un milieu communautaire normal.*

Brent White, gestionnaire de programme, Services résidentiels et de soutien de Brandon, a donné des précisions au sujet du programme de surveillance :

*À Brandon, nous avons élaboré quelque chose que nous appelons un « service de surveillance », qui ressemble aux services des soins à domicile, si vous voulez, pour les bénéficiaires en santé mentale. Des gens offrent des services de soutien aux personnes pour qu'elles réalisent leurs objectifs à long terme. Le bénéficiaire est habilité, car il travaille à atteindre ses buts, qui peuvent avoir trait à sa vie, aux études, à une profession ou à sa vie en société. De plus, nous avons accordé beaucoup d'attention à l'exécution de programmes sociaux de soutien[...]<sup>169</sup>.*

<sup>169</sup> 1<sup>er</sup> juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evd-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16evd-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Depuis, le programme de surveillance a été adopté dans d'autres régions du Manitoba. À Brandon, les surveillants, employés pour la plupart à temps partiel, s'occupent d'environ 150 clients chacun. Ils comptent dans une proportion à peu près égale des professionnels de la santé et des étudiants en psychologie, des personnes qui essaient d'intégrer le marché du travail et des aînés à la recherche de travail à temps partiel; près du tiers des surveillants sont eux-mêmes d'anciens clients des services de santé mentale.

M. Hajes a également souligné l'importance d'une participation plus importante de la collectivité :

*De plus, il fallait établir de solides partenariats avec d'autres organismes de services sociaux et de services de santé, des services hospitaliers, des médecins ainsi que des corps policiers, des districts scolaires, des propriétaires fonciers, des autorités du logement, et d'autres personnes. [...] Comme nous demandions à des partenaires communautaires de partager la responsabilité des services de santé mentale, nous devons également leur fournir des services de soutien.*

Enfin, M. Hajes a expliqué que la pénurie de médecins à Brandon a été un catalyseur de l'innovation :

*Nous avons un vaste effectif générique de travailleurs en santé mentale communautaire qui ont des titres de compétence en soins infirmiers psychiatriques, en psychologie et en travail social. Le Centre de santé mentale de Brandon employait un effectif semblable qui ne comprenait pas beaucoup de psychiatres et de médecins.*

*En fait, pour vous dire la vérité, nous avons eu des années de vaches maigres. À un moment donné, un psychiatre de Winnipeg venait passer deux ou trois jours par semaine pour signer les documents, et nous avions quelques médecins qui avaient une certaine expérience en santé mentale. Cela a amené les employés qui ne sont pas des professionnels de la santé à apprendre à répondre aux besoins. Les compétences de notre effectif sont bien meilleures, je crois, que ce que vous verriez dans la plupart des autres régions de santé mentale.*

**...Il fallait établir de solides partenariats avec d'autres organismes de services sociaux et de services de santé, des services hospitaliers, des médecins ainsi que des corps policiers, des districts scolaires, des propriétaires fonciers, des autorités du logement, et d'autres personnes.**

— **Albert Hajes**

**Le premier contact avec le système peut se faire dans un endroit bien connu, d'accès facile, situé au centre-ville de Brandon, près des transports en commun et d'autres services dont dépendent les clients des services de santé mentale.**

**Les responsables de la gestion intensive de cas s'occupent de personnes qui vivent dans la collectivité, mais qui ont besoin de soutien continu pour gérer leur vie de tous les jours.**

Actuellement, la coordination des divers programmes mis en œuvre à Brandon est assurée par une équipe de gestion qui se réunit toutes les deux semaines. Les programmes de santé

mentale reçoivent approximativement 10 p. cent des fonds dont dispose l'Office régional de la santé de Brandon, qui a préservé l'affectation budgétaire pour la santé mentale même au cours des années où les déficits planaient.

Le premier contact avec le système peut se faire dans un endroit bien connu, d'accès facile, situé au centre-ville de Brandon, près des transports en commun et d'autres services dont dépendent les clients des services de santé mentale. Ce centre communautaire entretient d'étroites relations professionnelles avec plusieurs services et organismes apparentés, notamment le Centre d'amitié de Brandon, un organisme autochtone vers lequel il est possible d'aiguiller des clients afin qu'ils reçoivent des traitements adaptés aux différences culturelles et qui est financé grâce à un contrat de services avec le programme de santé mentale.

**Des programmes visent également les jeunes et les personnes âgées.**

Les responsables de la gestion intensive de cas s'occupent de personnes qui vivent dans la collectivité, mais qui ont besoin de soutien continu pour gérer leur vie de tous les jours. Les Services d'hébergement et de réadaptation psychosociale aident leurs clients à trouver un logement locatif et à avoir accès au service de surveillance susmentionné. L'organisme Westman Crisis Services est un centre d'intervention téléphonique dirigé par du personnel infirmier qui fonctionne 24 heures sur 24 et sept jours sur sept; il assure un service mobile d'intervention d'urgence de même qu'une unité de stabilisation en situation de crise qui peut accueillir jusqu'à 8 personnes pendant environ cinq jours. Les personnes qui ont besoin de soins psychiatriques actifs en établissement peuvent être dirigés vers le Centre de psychiatrie pour adultes, un établissement de 25 lits qui offre des soins actifs et qui est rattaché au Centre de santé régional de Brandon.

Des programmes visent également les jeunes et les personnes âgées. Les Services de santé mentale pour les aînés desservent leurs clients à domicile; ceux qui ont besoin de soins actifs en établissement sont dirigés vers le Centre de psychiatrie gériatrique. Celui-ci comprend une unité de soins psychiatriques actifs de 22 lits rattachée au Centre de santé régional de Brandon, et 70 p. cent des personnes qui y sont admises peuvent ultérieurement recevoir leur congé et retourner dans leur logement. Le Centre de traitement des adolescents et des enfants du Programme de santé mentale de Brandon est situé dans un établissement à proximité d'une école secondaire; il privilégie le retour de chaque jeune souffrant d'une maladie mentale dans son école, sa famille et sa collectivité.

#### **5.4 ASSURER LA TRANSITION AUX SERVICES COMMUNAUTAIRES**

Même si de nombreuses régions du pays telles que celle de Brandon mettent en place des services communautaires, le Comité est d'avis qu'il reste encore beaucoup à faire pour que les personnes atteintes de maladie mentale aient accès aux services dont elles ont besoin pour mener une vie productive dans la collectivité. Les personnes qui ont répondu au deuxième sondage électronique du Comité ont indiqué dans une proportion de 80 p. cent que les

services nécessaires aux personnes ayant une maladie mentale n'étaient pas offerts dans leur collectivité<sup>170</sup>.

Si elles n'ont pas accès aux services dans la collectivité, les personnes aux prises avec la maladie mentale doivent se tourner vers les services en établissement qui sont généralement beaucoup plus coûteux et souvent moins utiles. Nancy Beck, directrice de Connections Clubhouse à Halifax a relaté la situation d'un ancien combattant schizophrène de 72 ans :

*[Clyde] a besoin de quelques heures de soins personnels par semaine, et d'une personne qui vient l'aider à préparer ses repas. En tant que bénéficiaire de soins de santé mentale, il ne peut pas bénéficier de soins à domicile, et on a recommandé, à son grand dam, de lui dispenser des soins de longue durée. Nous estimons qu'il ne coûterait que 400 \$ par mois pour exaucer le souhait de Clyde et l'aider à rester dans l'appartement qu'il occupe depuis quinze ans<sup>171</sup>.*

**Les personnes qui ont répondu au deuxième sondage électronique du Comité ont indiqué dans une proportion de 80 p. cent que les services nécessaires aux personnes ayant une maladie mentale n'étaient pas offerts dans leur collectivité. Si elles n'ont pas accès aux services dans la collectivité, les personnes aux prises avec la maladie mentale doivent se tourner vers les services en établissement qui sont généralement beaucoup plus coûteux et souvent moins utiles**

D'autres témoins ont souligné l'importance des logements accessibles et adéquats en tant que moyen pour permettre aux personnes souffrant de maladie mentale de continuer à vivre dans la collectivité et en tant que pierre angulaire de la réforme du système de santé mentale. Comme l'a expliqué Stephen Ayr, directeur de la recherche, Capital District Health Authority, à Halifax :

**Selon un rapport de l'Institut canadien d'information sur la santé (ICIS), les habitudes de patients en santé mentale en ce qui a trait à l'utilisation des ressources hospitalières donnent à entendre qu'encore beaucoup de services pourraient être transférés dans la collectivité.**

*Vous comprendrez très bien si je vous dis seulement que, si on ne règle pas la question du logement, il est fort probable que toute réforme provinciale de la santé mentale ne changera rien au problème<sup>172</sup>.*

Des témoins ont signalé au Comité que les fonds qui étaient auparavant affectés aux soins en établissement ne sont pas toujours transférés dans le secteur communautaire. Jocelyn Greene, directrice exécutive, Stella Burry Community Services, à St. John's, a parlé de l'incidence des compressions dans le secteur de la santé au cours des années 1990 :

<sup>170</sup> Ascentum Incorporated, Rapport final sur le sondage électronique du Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, 2005, p. 28-29.

<sup>171</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>172</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*En particulier, en 1995, les compressions du gouvernement fédéral ont provoqué d'autres compressions dans notre province en santé et, en particulier, la fermeture de 97 lits sur 127 lits voués aux soins de longue durée à l'hôpital Waterford, l'institut psychiatrique provincial. Il n'est nullement exagéré de dire qu'aucune des économies qu'on a réalisées avec la fermeture de ces lits n'ont été réinvesties en milieu communautaire. J'ignore ce qu'on en a fait, mais, chose certaine, ceux d'entre nous qui œuvrons en milieu communautaire n'en avons nullement profité<sup>173</sup>.*

D'autres données probantes concernant les difficultés auxquelles se heurtent les services communautaires de santé mentale proviennent d'un sondage effectué dans ce secteur par la Fédération des programmes communautaires de santé mentale et de traitement des toxicomanies de l'Ontario en 2002. Le sondage a permis d'établir ce qui suit :

- Depuis 1992, la plupart des 212 organisations membres de la Fédération ont subi une réduction nette de 20 p. cent du financement provincial des programmes de base, compte tenu de l'augmentation des coûts de fonctionnement au cours de la période.
- Quatre-vingt pour cent des répondants ont dû suspendre temporairement des programmes afin de faire face aux pressions budgétaires. Vingt-cinq pour cent de ces programmes ont dû être supprimés.
- Près de la moitié des personnes qui ont besoin des services offerts par les organisations membres de la Fédération doivent attendre au moins huit semaines avant d'y avoir accès.
- La période d'attente avant d'avoir accès à un nombre considérable de programmes (18 p. cent) est d'un an ou plus<sup>174</sup>.

Le Comité a appris que le gouvernement de l'Ontario effectue actuellement d'importants investissements dans les services de santé mentale dans la collectivité, comme le font la plupart des autres provinces. Au cours des deux dernières années, les budgets de base des programmes communautaires de santé mentale ont été majorés pour la première fois en 12 ans en Ontario. Il est clair qu'il reste malgré tout beaucoup à faire. Carrie Hayward, directrice, Division de la santé mentale et des dépendances, ministère de la Santé et des Soins de longue durée de l'Ontario, a déclaré ce qui suit au Comité :

*Il existe en Ontario 6 750 unités de logement avec soutien destinées aux personnes souffrant de maladie mentale ou de toxicomanie; toutefois, le Forum provincial des groupes de travail chargés d'étudier la mise en*

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<sup>173</sup> 15 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>174</sup> Fédération des programmes communautaires de santé mentale et de traitement des toxicomanies de l'Ontario, *Outcomes and Effectiveness: The Success of Community Mental Health and Addiction Programs*, 2003, p. 13.

*œuvre de la réforme des services de santé mentale a demandé qu'il y en ait 10 000 de plus à l'échelle de la province*<sup>175</sup>.

De façon plus générale, selon un rapport de l'Institut canadien d'information sur la santé (ICIS), les habitudes de patients en santé mentale en ce qui a trait à l'utilisation des ressources hospitalières donnent à entendre qu'encore beaucoup de services pourraient être transférés dans la collectivité. Dans le rapport, une analyse de l'hospitalisation de patients en santé mentale indique que ceux-ci sont plus susceptibles d'être hospitalisés pour des périodes prolongées que tout autre groupe de patients. Le rapport présente les faits suivants :

**Près du quart des patients atteints de troubles mentaux qui font un séjour de 19 jours ou plus dans un hôpital de soins actifs sont en fait des patients en soins de longue durée qui occupent des lits dans un établissement de soins actifs.**

**De nombreux patients sont gardés dans des établissements de soins actifs parce qu'il n'y a pas d'autres solutions dans la collectivité**

Bien que le groupe des patients en santé mentale ait été responsable de la plus faible proportion de toutes les hospitalisations (un peu plus de 3 p. cent), il arrivait troisième parmi tous les groupes pour le nombre de jours d'hospitalisation (7,4 p. cent), et premier pour la durée moyenne de séjour, à 14 jours, soit plus du double de la moyenne nationale<sup>176</sup>.

Il précise également ce qui suit :

À la différence des autres groupes, seulement 50 p. cent du groupe des patients en santé mentale ont été hospitalisés pendant 7 jours ou moins. Près d'un quart des patients en santé mentale ont été hospitalisés pendant 19 jours ou plus, un taux presque 3 fois plus élevé que celui de tous les groupes combinés (7 p. cent)<sup>177</sup>.

Selon l'Organisation de coopération et de développement économique (OCDE), les patients en soins actifs sont ceux dont le séjour moyen à l'hôpital est de 18 jours ou moins; les patients dont le séjour dépasse 18 jours sont des patients en soins de longue

**L'utilisation de lits des établissements de soins actifs pendant une période prolongée dans le but de répondre aux besoins de patients ayant des troubles mentaux constitue une très mauvaise affectation de ressources précieuses et peu abondantes.**

durée. Près du quart des patients atteints de troubles mentaux qui font un séjour de 19 jours ou plus dans un hôpital de soins actifs sont en fait des patients en soins de longue durée qui occupent des lits dans un établissement de soins actifs. Même si la nature de la maladie mentale peut expliquer les longs séjours en établissement, on peut raisonnablement présumer

<sup>175</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>176</sup> ICIS, *Tendances des hospitalisations et de la durée moyenne du séjour au Canada, 2003-2004 et 2004-2005*, 30 novembre 2005, p. 11.

<sup>177</sup> *Ibid.*, p. 14.

que de nombreux patients sont gardés dans des établissements de soins actifs parce qu'il n'y a pas d'autres solutions dans la collectivité.

En fait, c'est ce que des témoins ont déclaré au Comité. À cet égard, Roy Muişe a raconté ce qu'il a vécu :

*Je me rappelle que, lorsque j'étais sur le point de sortir de l'hôpital, je n'avais nulle part où aller parce que je n'avais pas de revenu et que je n'avais pas d'argent. J'ai passé 13 jours à l'hôpital, uniquement parce que je n'avais aucun endroit où aller. Compte tenu des périodes creuses dans nos antécédents professionnels, nous avons beaucoup de difficulté à trouver un logement et à faire un dépôt pour les dommages éventuels, par exemple, pendant que nous tentons de changer complètement notre vie. Il est effectivement essentiel de prendre des initiatives dans le domaine du logement. C'est une chose certaine<sup>178</sup>.*

L'utilisation de lits des établissements de soins actifs pendant une période prolongée dans le but de répondre aux besoins de patients ayant des troubles mentaux pour des raisons semblables à celles qui ont gardé Roy Muişe à l'hôpital tout à fait inutilement constitue une très mauvaise affectation de ressources précieuses et peu abondantes; d'ailleurs, selon toute probabilité, le rétablissement du patient s'en trouve retardé. Le Comité croit que, malheureusement, c'est précisément ce qui se produit actuellement partout au pays.

## 5.5 LA NÉCESSITÉ D'UN FONDS DE TRANSITION

Comme on l'a dit, tout indique que, s'il faut se garder de voir dans les services communautaires un moyen de réaliser des économies, le financement d'un système reposant principalement sur des services communautaires ne coûtera pas plus cher au gouvernement que le financement du système actuel, fondé essentiellement sur des services institutionnels. Cela étant, pourquoi donc les autorités n'ont-elles pas réussi à faire aboutir la transition à un système de services communautaires compte tenu des nombreux avantages de cette formule pour les personnes atteintes de maladie mentale? Plusieurs raisons expliquent que la transition vers un ensemble intégré de services de santé mentale dispensés dans la collectivité progresse inégalement dans les provinces et les territoires.

**Les économies générées par le rétrécissement du secteur institutionnel ne se matérialiseront pas d'un coup, mais progressivement, au fur et à mesure de l'élimination des services institutionnels.**

**Les deux systèmes devront longtemps fonctionner en parallèle, d'où des coûts additionnels.**

**Rien ne garantit que l'argent économisé par la fermeture d'un grand établissement finira par se retrouver dans le budget de la santé mentale.**

<sup>178</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Les plus importantes tiennent à la difficulté de transformer la formule de financement des services. Dans un récent article sur la restructuration de la politique de l'Ontario en matière de santé mentale, on faisait valoir ce qui suit :

Cependant, la fermeture des hôpitaux psychiatriques exigera d'abord une volonté politique et ensuite une mise de fonds initiale pour financer la mise en place des services communautaires qui prendront le relais. Or, un cercle vicieux paralyse le processus : les fonds nécessaires à la mise en place des services médico-sociaux de proximité sont monopolisés par les hôpitaux et les hôpitaux ne peuvent pas fermer en l'absence de ces services. Il faudra donc prévoir un financement de transition<sup>179</sup>.

À cet égard, il importe de garder trois choses en mémoire. Premièrement, les économies générées par le rétrécissement du secteur institutionnel ne se matérialiseront pas d'un coup, mais progressivement, au fur et à mesure de l'élimination des services institutionnels. En conséquence, la réforme ne produira pas dans l'immédiat d'économies à partir desquelles financer l'établissement de nouveaux services

**Pour ces raisons, le Comité pense qu'il faut instituer un Fonds de transition en santé mentale (FTSM).**

**Il s'agira d'un fonds temporaire destiné à couvrir les coûts de transition et à accélérer l'implantation d'un système de services médico-sociaux communautaires.**

médico-sociaux communautaires. Deuxièmement, comme l'élimination progressive de l'ancien système et l'implantation du nouveau prendront du temps, les deux systèmes devront longtemps fonctionner en parallèle, d'où des coûts additionnels. Troisièmement, rien ne garantit que l'argent économisé par la fermeture d'un grand établissement finira par se retrouver dans le budget de la santé mentale.

Pour ces raisons, le Comité pense qu'il faut instituer un Fonds de transition en santé mentale (FTSM) au moyen duquel le gouvernement du Canada mettra à la disposition des provinces et des territoires des ressources réservées au financement des services et mesures de soutien qui contribueront à faciliter la transition vers un système intégré de services locaux pour ceux qui souffrent d'une maladie mentale. Il s'agira d'un fonds temporaire destiné à couvrir les coûts de transition et à accélérer l'implantation d'un système de services médico-sociaux communautaires.

**C'est un vrai fonds de transition conçu uniquement pour financer les coûts associés à la réforme de l'organisation des soins de santé mentale durant la phase de transition d'un système à l'autre.**

**Il nous semble que la formule du fonds de transition est la mieux adaptée à l'investissement, par le gouvernement fédéral, de crédits dans ce qui est un secteur de compétence provinciale.**

Une fois que le nouveau système aura trouvé sa « vitesse de croisière » — c'est-à-dire quand tous les nouveaux services seront en place — les provinces et les territoires seront en mesure de le financer au même coût que l'ancien. Ainsi, les crédits fédéraux consentis aux provinces et aux territoires pour les aider à faire le saut constitueront véritablement un fonds de transition : ils ne représenteront pas une obligation à long terme pour le gouvernement

<sup>179</sup> M. Wiktorowicz (2005), « Restructuring mental health policy in Ontario: Deconstructing the evolving welfare state », dans *Canadian Public Administration*, vol. 48, n° 3, p. 392.

fédéral pas plus qu'ils n'entraîneront une augmentation des dépenses pour les provinces et les territoires.

Le Fonds de transition en santé mentale sera différent des autres fonds fédéraux dits « de transition » comme le Fonds pour l'adaptation des soins de santé primaires, par exemple. En effet, les initiatives fédérales de ce genre ont trop souvent entraîné la création de nouveaux programmes qui soit exigent des provinces qu'elles y consacrent de nouveaux crédits, soit sont abandonnés une fois que les programmes fédéraux qui sont à leur origine sont arrivés à terme. Ce ne sont pas vraiment des mesures de transition dans la mesure où elles obligent les gouvernements des provinces et des territoires à faire des dépenses additionnelles à long terme.

Le Comité a pris bien soin de formuler ses recommandations de manière à éviter cela dans le cas du Fonds de transition en santé mentale. Ce qu'il entrevoit, c'est un vrai fonds de transition conçu uniquement pour financer les coûts associés à la réforme de l'organisation des soins de santé mentale durant la phase de transition d'un système à l'autre.

Il nous semble que la formule du fonds de transition est la mieux adaptée à l'investissement, par le gouvernement fédéral, de crédits dans ce qui est un secteur de compétence provinciale (la prestation de services de santé mentale). Comme le gouvernement fédéral n'est pas responsable de la prestation des services de santé mentale dans les provinces et les territoires, il ne lui appartient pas de déterminer l'emploi optimal des fonds fédéraux. Il faut pour cela une connaissance des besoins que seule l'expérience peut procurer. Par conséquent, ce sont les provinces et les territoires qui doivent décider de l'allocation des sommes qui leur seront accordées.

Cette solution n'a évidemment rien de bien nouveau. Elle est conforme à de nombreuses ententes conclues récemment en matière de santé entre le gouvernement fédéral et les gouvernements des provinces et des territoires. En fait, depuis la création du Transfert canadien en matière de santé et de programmes sociaux en 1995, les provinces ont la haute main sur l'emploi des transferts fédéraux concernant la santé et les affaires sociales.

**Il est cependant normal que le gouvernement demande des comptes, d'une manière ou d'une autre, sur l'usage des fonds qu'il dispense, puisqu'il est comptable, envers la population, du bon usage des fonds publics.**

Bonnie Arnold, de la division de l'Île-du-Prince-Édouard de l'Association canadienne pour la santé mentale (ACSM), a insisté sur l'importance de la souplesse du financement fédéral pour répondre aux besoins locaux variés des fournisseurs de services de santé mentale, et a parlé des soins à domicile pour illustrer son propos :

*Le terme « soins à domicile » a un sens très différent d'une province à une autre. Nous croyons qu'il est essentiel que le financement transféré par le gouvernement fédéral offre suffisamment de souplesse pour que l'Î.-P.-É. puisse l'utiliser de la façon la plus créative et la plus efficace*

*possible pour se doter des services requis en santé mentale, et qu'il ne soit pas lié à un type de service en particulier<sup>180</sup>.*

Il est cependant normal que le gouvernement demande des comptes, d'une manière ou d'une autre, sur l'usage des fonds qu'il dispense, puisqu'il est comptable, envers la population, du bon usage des fonds publics. En l'occurrence, le gouvernement fédéral et les Canadiens en général doivent avoir l'assurance que l'argent a) est consacré à des activités relatives à la santé mentale et b) augmente le total des dépenses consacrées par les provinces et les territoires à l'amélioration de la santé mentale et au traitement de la maladie mentale.

Par ailleurs, le Comité souhaite que ces fonds viennent s'ajouter non seulement aux dépenses des provinces et des territoires en la matière, mais aussi à l'augmentation du financement de la santé mentale associée à la progression normale des dépenses de santé des provinces et territoires. Autrement dit, ces fonds doivent représenter un véritable surcroît de dépenses.

**Il faut prévoir un mécanisme de réserve pour garantir que les nouveaux crédits fédéraux sont effectivement employés aux fins prévues.**

Il importe cependant de préciser que le Comité ne prescrit pas les services nouveaux ou améliorés dans lesquels les provinces et territoires devront investir. Ce sont les autorités provinciales et territoriales qui décideront, en fonction de leurs besoins particuliers, si elles doivent affecter les nouveaux crédits à l'amélioration ou l'extension de services existants ou à la création de nouveaux services. Ensuite, si des provinces ou des territoires sont en mesure de réaliser des économies grâce à des gains de productivité, elles auront toute latitude pour décider de l'emploi des économies en question.

Beaucoup d'analystes sont d'avis qu'il faut prévoir un mécanisme de réserve pour garantir que les nouveaux crédits fédéraux sont effectivement employés aux fins prévues. Comme l'a dit au Comité la présidente de la Fédération canadienne des infirmières et infirmiers en santé mentale, Christine Davis :

**On avait eu recours à de tels fonds réservés durant la phase initiale de mise en œuvre de la Politique nationale en matière de santé mentale en Australie.**

*Les fonds des ministères de la Santé sont attribués aux autorités de la santé qui s'empressent de faire ce qui est le plus pressant, c'est-à-dire réduire les listes d'attente pour la chirurgie de la hanche, du genou, la chirurgie cardiaque et ainsi de suite. Ces fonds ne sont jamais réservés à la santé mentale, et ils ne seront jamais consacrés à la maladie mentale ni aux toxicomanies. La maladie mentale et les toxicomanies sont au bas de l'échelle des soins de santé et les personnes aux prises avec ces problèmes sont perçues comme étant moins méritantes que les autres. Il faut que ces fonds soient réservés à la santé mentale dès le départ<sup>181</sup>.*

<sup>180</sup> 16 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evc-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evc-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>181</sup> 20 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

D'autres craignent par contre que ce type d'intervention n'ait pour effet de limiter dans une certaine mesure le montant total des fonds disponibles, mais même eux admettent que, vu l'urgence d'accélérer le changement dans le secteur de la santé mentale, l'idée de fonds réservés n'est pas mauvaise.

Cette idée a été reprise par le D<sup>r</sup> John Service, président de l'Alliance canadienne pour la maladie mentale et la santé mentale :

*Vous aviez raison de dire, hier, monsieur le président, que vous vous trouvez dans une situation impossible avec ce genre de fonds. D'un côté, on peut faire une sélection minutieuse, quand les temps sont durs. Nous savons que cela s'est fait au pays. Je suis dans ce métier depuis 30 ans, et je sais que cela s'est produit à plusieurs reprises. Les fonds désignés sont très vulnérables. Ils sont isolés, ce qui ne fait qu'accroître la séparation. Ces fonds ciblés et désignés peuvent enclencher une transformation. Ils peuvent servir à se procurer cette transformation. Si on tient compte des changements structurels dont on aura besoin pour le long terme, et si on procède de façon correcte, cela pourrait être utile<sup>182</sup>.*

Dans son rapport *Politiques et programmes de certains pays en matière de santé mentale*, le Comité a noté que l'on avait eu recours à de tels fonds réservés durant la phase initiale de mise en œuvre de la Politique nationale en matière de santé mentale en Australie<sup>183</sup>. Tous les ordres de gouvernement de ce pays se sont engagés à pratiquer une certaine forme de protection budgétaire de manière que les injections de fonds fédéraux additionnels ne donnent pas lieu à des réductions concomitantes du financement consenti par les États et les territoires. L'entente conclue entre les gouvernements pour protéger les ressources consacrées à la santé mentale comportait en particulier les deux éléments suivants :

- les parties s'engageaient à maintenir les niveaux courants de dépenses en santé mentale;
- les parties s'engageaient aussi à réinvestir dans les programmes de santé mentale les ressources libérées par l'élimination et la rationalisation des services.

M. Dermot Casey, secrétaire adjoint chargé des priorités sanitaires et de la prévention du suicide au ministère de la Santé et de la Vieillesse de l'Australie, a dit au Comité que les mesures de protection des dépenses en santé mentale avaient été si efficaces qu'elles étaient devenues superflues :

*En fait, l'une des craintes du gouvernement fédéral, il y a dix ans, c'était que si nous donnions de l'argent pour la santé mentale, les États et les*

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<sup>182</sup> 21 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>183</sup> Comité sénatorial des affaires sociales, des sciences et de la technologie, novembre 2004, Rapport 2 — *La maladie mentale, la santé mentale et la toxicomanie, Politiques et programmes de certains pays en matière de santé mentale*, p. 9, <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/rep-f/report2/repintnov04vol2-f.pdf>.

*Territoires se contenteraient de le prendre et de le consacrer à autre chose. Nous avons une entente stipulant qu'ils maintiendraient leur niveau de financement si le gouvernement fédéral augmentait le montant total. Nous avons suivi à la trace l'argent dépensé, et les États et Territoires devaient faire rapport à une instance de contrôle des dépenses. Nous n'avons plus besoin de ce système aujourd'hui, dix ans plus tard, parce que, conscients de l'importance de cet aspect à leur niveau et de la controverse politique que cela occasionnerait dans les collectivités, les gouvernements ne dépenseraient pas ces montants à d'autres fins<sup>184</sup>.*

L'idée a beau avoir du mérite, le Comité ne croit pas possible pour le moment d'instituer un système de fonds réservés permettant de rendre compte de l'emploi des fonds jusqu'au niveau local. En fait, il a fait faire une étude de la viabilité de cette formule en santé mentale au niveau des administrations régionales de la santé. Les chercheurs ont conclu que non seulement il y avait un manque de coordination de l'information sur la santé mentale au niveau provincial et au niveau national, mais qu'il y avait aussi des lacunes au niveau de l'évaluation des besoins de la population, du profilage des services et des liens entre les volets santé, services sociaux, justice et éducation du système de soins<sup>185</sup>. Bref, le système d'information sur la santé qui permet de contrôler les dépenses en santé, notamment en santé mentale, n'est pas adapté à ces fins.

**Vu les connaissances de ses membres sur les politiques en santé mentale et les pratiques exemplaires et son indépendance vis-à-vis du gouvernement, la Commission canadienne sur la santé mentale est mieux placée que Santé Canada pour superviser l'administration du Fonds de transition.**

Le Comité estime néanmoins possible d'établir, sous l'égide de la Commission canadienne de la santé mentale, des procédures propres à garantir que les fonds de transition servent aux fins prévues. Les sommes prélevées sur le Fonds devraient être administrées par la Commission canadienne de la santé mentale, dont la création a été agréée par tous les ministres de la Santé à l'exception de celui du Québec et annoncée officiellement par le ministre fédéral de la Santé le 24 novembre 2005<sup>186</sup>. Vu les connaissances de ses membres sur les politiques en santé mentale et les pratiques exemplaires et son indépendance vis-à-vis du gouvernement, la Commission est mieux placée que Santé Canada pour superviser l'administration du Fonds de transition.

Pour le Comité, il faut donner la priorité aux mesures visant à améliorer les conditions de vie des personnes atteintes d'une maladie mentale grave, adultes et enfants. La formule la plus avantageuse pour ces personnes, c'est celle de la prestation d'un éventail de soins pleinement intégrés. Elle présente par ailleurs l'avantage de mettre ces services à la disposition aussi des personnes moins gravement atteintes.

**Le Comité tient particulièrement à ce que, dans l'élaboration des services communautaires de santé mentale, l'on mette l'accent en particulier sur les besoins des enfants.**

<sup>184</sup> *Ibid.*, p. 10.

<sup>185</sup> E. Pepler (octobre 2005), *An evaluation of service delivery and financial data within Alberta for the purpose of evaluating 'ring-fence' protection of mental health funding*, p. 17.

<sup>186</sup> On trouvera au chapitre 16, « Initiatives nationales en santé mentale », toute une section sur la création et la composition de la Commission.

Par exemple, des services de première ligne locaux sont indispensables en tant que premier point de contact à la fois pour les personnes gravement atteintes qui ont besoin d'être aiguillées vers des services plus intensifs et spécialisés et pour celles qui peuvent être soignées à ce niveau-là. De même, l'offre de services transversaux profitera à toutes les personnes atteintes de maladie mentale, bien que la priorité d'accès à certains services, comme le logement assisté, devra être accordée aux personnes gravement atteintes.

Le Comité tient particulièrement à ce que, dans l'élaboration des services communautaires de santé mentale, l'on mette l'accent en particulier sur les besoins des enfants. Comme on le verra plus en détail dans le prochain chapitre, les enfants et les jeunes sont trop souvent laissés pour compte, même dans les discussions sur la manière d'améliorer le système de santé en général. Le Comité estime indispensable de remédier à cet état de choses.

Le Comité recommande :

9	<p><b>Que le gouvernement du Canada crée un Fonds de transition en santé mentale pour accélérer la transition vers un système où la prestation des services en santé mentale se fera essentiellement dans la collectivité.</b></p> <p><b>Que les sommes versées dans ce fonds soient mises à la disposition des provinces et des territoires au prorata de la population et que la gestion du Fonds soit confiée à la Commission canadienne de la santé mentale dont la création a été entérinée par tous les ministres de la Santé à l'exception de celui du Québec.</b></p> <p><b>Que le Fonds serve à financer des activités :</b></p> <ul style="list-style-type: none"> <li>• qui autrement n'auraient pas vu le jour, c'est-à-dire qu'elles représentent un surcroît de dépenses par rapport aux dépenses courantes augmentées de la hausse annuelle normale des dépenses globales de santé;</li> <li>• qui faciliteront la transition vers l'établissement d'un système reposant essentiellement sur la prestation des services en santé mentale dans la collectivité.</li> </ul> <p><b>Que, dans le financement d'activités à même le Fonds, l'on accorde la priorité aux personnes souffrant d'une maladie mentale grave et persistante et que l'on s'intéresse en particulier aux besoins des enfants et des jeunes en matière de santé mentale.</b></p>
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## 5.6 LES VOLETS DU FONDS DE TRANSITION EN SANTÉ MENTALE

Nous traiterons ici des principaux services qui pourront être financés à même le Fonds de transition en santé mentale. Nous parlerons du montant total nécessaire au financement de ces mesures au chapitre 16.

Nous le répétons, le Fonds de transition devrait comporter deux volets : l'Initiative d'aide au logement pour la santé mentale, qui permettra de financer la constitution d'un parc de logements abordables et appropriés de même que des suppléments au loyer pour que les personnes atteintes d'une maladie mentale qui n'en auraient pas autrement les moyens puissent vivre dans un logement à loyer libre; et le Panier de services communautaires qui aidera les provinces à fournir aux personnes atteintes de maladie mentale un éventail de services directement dans la collectivité.

### 5.6.1 L'Initiative d'aide au logement pour la santé mentale

On ne saurait surestimer l'importance d'un logement convenable pour les personnes qui souffrent de maladie mentale, surtout quand il s'agit d'une maladie grave. Des études montrent que de 30 à 40 p. cent des sans-abri ont des problèmes de santé mentale et que de 20 à 25 p. cent ont aussi des troubles concomitants, à savoir en plus des problèmes de toxicomanie. C'est dire l'étendue du problème.

**De 30 à 40 p. cent des sans-abri ont des problèmes de santé mentale et que de 20 à 25 p. cent ont aussi des troubles concomitants, à savoir en plus des problèmes de toxicomanie.**

**De 1980 à 2000, le nombre d'unités de logement à prix abordables créé par le gouvernement du Canada a chuté, passant de 24 000 à 940**

Le message est partout le même. Christine Davis, la présidente de la Fédération canadienne des infirmières et infirmiers en santé mentale, l'a présenté en ces termes :

*Le logement est une forme de protection contre la maladie. Le logement est aussi une protection contre les caprices de la maladie mentale, contre les voix et contre les peurs. Le gouvernement fédéral doit aborder la question du manque de logements abordables<sup>187</sup>.*

Il est extrêmement difficile de trouver des logements convenables. La directrice de la Schizophrenia Society of Saskatchewan Carol Solberg a expliqué au Comité que :

*La plupart des gens qui reçoivent de l'aide sociale vivent dans de très petits logements, souvent dans des quartiers pas toujours très sécuritaires. Les logements sont parfois insalubres et ne favorisent pas une bonne santé mentale. Je crois que quiconque jouissant d'une bonne santé mentale, mais qui vivrait dans ce genre de conditions finirait par être malade ou, à tout le moins, déprimé<sup>188</sup>.*

Jan House a parlé au Comité du mal qu'elle a eu à trouver un logement convenable pour sa fille à Halifax :

<sup>187</sup> 20 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>188</sup> 2 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*L'environnement physique est particulièrement important pour les personnes atteintes de maladie mentale; cependant, comme elles n'ont généralement qu'un maigre revenu ou aucun moyen de subsistance, elles sont souvent forcées de vivre dans les pires quartiers où le taux de criminalité est élevé et où la drogue et la violence règnent. Pour pouvoir vivre dans un environnement sûr et favorable, ma fille a été forcée de déménager trois fois en un an<sup>189</sup>.*

Les témoins ont parlé des répercussions des compressions budgétaires fédérales sur l'offre de logements abordables. Selon l'Association canadienne pour la santé mentale, « [d] e 1980 à 2000, le nombre d'unités de logement à prix abordables créé par le gouvernement du Canada a chuté, passant de 24 000 à 940 »<sup>190</sup>. Linda Chamberlain, du Dream Team de Toronto, a insisté sur la pénurie de logements abordables :

*C'est ça, le problème. Nous n'avons pas suffisamment de logements. En général, il y a un délai d'attente de 10 ans. Certains d'entre nous ont dû attendre cinq ans avant d'obtenir un logement. C'est pourquoi nous avons besoin de plus de logements. On n'en construit pas assez<sup>191</sup>.*

Bonnie Arnold, de la division de l'Île-du-Prince-Édouard de l'ACSM, a exposé les difficultés des organismes qui cherchent à aider les personnes atteintes de maladie mentale à obtenir un logement et les services dont elles ont besoin dans le contexte de la réduction des subventions fédérales au logement.

*Sur le sujet du logement, un autre point qui a été porté à l'attention du groupe de travail est le fait que les programmes de logements subventionnés qui étaient autrefois soutenus par le gouvernement fédéral n'existent plus. Il est vrai que de nouveaux fonds ont été débloqués pour aider à la construction de logements, mais il est impossible pour les agences de rendre les loyers abordables pour les locataires, qui sont souvent des célibataires à faible revenu, et d'offrir en même temps des programmes appropriés<sup>192</sup>.*

Des témoins ont aussi fait valoir au Comité que les programmes d'aide aux personnes atteintes de maladie mentale sont efficaces. Le directeur de la Coast Foundation Society/Coast Mental Health Foundation Darrell Burnham a dit au Comité :

**Les programmes d'aide aux personnes atteintes de maladie mentale sont efficaces.**

<sup>189</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>190</sup> Association canadienne pour la santé mentale (avril 2005), mémoire soumis au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie.

<sup>191</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>192</sup> 16 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evc-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/22evc-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Nous servons beaucoup plus de 2 000 personnes. Je veux insister sur deux catégories de services. Tout d'abord, nous fournissons des logements subventionnés. En fait, nous avons été les pionniers du logement subventionné pour les personnes ayant une maladie mentale en 1974 et nous servons maintenant plus de 544 personnes dans différents types de logements partout dans le sud-ouest de la Colombie-Britannique, dans des quartiers agréables. Nous avons constaté que c'est non seulement d'un bon rapport coût-efficacité, en ce sens que cela garde les gens en santé et évite l'hospitalisation, mais aussi que les gens s'insèrent dans la collectivité. Ce ne sont pas des endroits qui se font remarquer et suscitent de l'inquiétude dans les quartiers en question. Donc, le logement subventionné fonctionne<sup>193</sup>.*

Suzanne Crawford, directrice de programme des LOFT Community Services à Toronto, a vanté les atouts du modèle des logements supervisés :

*Pourquoi est-ce que le logement supervisé fonctionne? Nous pensons que ça fonctionne parce que nous visons la guérison et l'indépendance. Nous l'avons entendu encore et encore. Nous mettons l'accent sur la sécurité. Nous mettons l'accent sur l'espace physique. Nous mettons l'accent sur le soutien pratique 24 heures sur 24.*

*Comme je l'ai dit, nous avons besoin de nos psychiatres. Nous avons besoin de nos cliniciens, mais vous savez quoi? Ils vont dans les foyers. Ils sont là pendant une heure, puis ils partent. Qui est là 24 heures sur 24? C'est le logement supervisé, et c'est le logement supervisé dans le cadre d'un modèle psychosocial. Ça offre une sécurité. Ça offre une paix d'esprit. Ça offre de la souplesse<sup>194</sup>.*

Phillip Dusfresne du Dream Team parle d'expérience :

*J'ai déjà vécu dans la rue; aujourd'hui, je suis membre du Dream Team, un projet qui a vu le jour grâce aux conseils des Mental Health and Housing Services, en 1999.*

*Les logements avec services de soutien ont changé notre vie; nous en donnons une preuve vivante, et nous racontons notre histoire aux politiciens des divers ordres de gouvernement, aux organismes de services sociaux, aux sociétés de bienfaisance, aux étudiants des écoles secondaires et des universités, aux groupes de consommateurs et à d'autres institutions.*

<sup>193</sup> 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>194</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*Les personnes qui vivent dans des logements avec services de soutien sont indépendantes. On nous a tous attribué un travailleur de soutien, et nous pouvons aller le voir si nous en avons besoin. Le travailleur de soutien peut nous aider à obtenir des prestations d'aide sociale. Il peut nous aider à préparer un curriculum vitae si nous voulons chercher un emploi. Il peut aussi nous aider à prendre rendez-vous chez le médecin ou le dentiste, ou nous aider dans nos activités quotidiennes, si nous ne nous sentons pas bien. Mais, en général, nous vivons de façon indépendante. Nous préparons nous-mêmes nos repas, nous faisons le ménage, nous faisons les courses et tout le reste. La plupart d'entre nous n'ont pas besoin d'un soutien 24 heures sur 24<sup>195</sup>.*

Le Comité a aussi entendu parler de diverses activités innovatrices dans le secteur public et dans le secteur non gouvernemental. La coprésidente de L'Abri en Ville de Montréal, Audrey Bean :

*Nous travaillons avec les établissements psychiatriques pour choisir les personnes qui profiteraient de ce mode de vie particulier. Nous nous occupons de deux aspects qui sont essentiels à la stabilité d'une personne ayant une maladie mentale. Le premier, c'est un logement permanent, un foyer, un endroit où elles peuvent inviter des gens, un endroit qui renforce leur sentiment d'identité, et à partir duquel elles peuvent ensuite renouer les liens avec leurs familles. Prenons l'exemple de la sœur de Maria, si elle pouvait trouver un mode de vie séparé, il arrive parfois que cela permette de rétablir de façon assez extraordinaire la relation avec la famille.*

*Nous offrons ensuite un soutien social, c'est-à-dire que nous organisons des soupers, les gens se rendent visite et nous assurons ce pont vers la collectivité pour une personne qui a souffert de l'isolement que connaissent si souvent les personnes ayant une maladie mentale.*

*Il s'agit d'un modèle simple qui peut être mis sur pied par toute collectivité. Nous sommes une centaine de personnes, nous avons 30 résidents et environ 60 à 70 bénévoles, et un conseil d'administration d'une vingtaine de personnes. Nous recevons maintenant une subvention. Nous avons reçu une subvention de Développement des ressources humaines Canada, et nous en avons maintenant une de la Fondation McConnell, pour reproduire notre modèle dans d'autres collectivités au Canada<sup>196</sup>.*

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<sup>195</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>196</sup> 21 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Et David Nelson, directeur de la division de la Saskatchewan de l'ACSM, a parlé au Comité d'une

*...initiative nouvelle et positive de notre province qui est à mon avis promise à un grand avenir. Il s'agit du Saskatchewan Rental Housing Supplement [...] Il s'agit d'aider les personnes qui ont un handicap quelconque à améliorer leur logement, et cela dépasse de loin l'installation de rampes qu'on voit partout et les réaménagements des salles de bains dont ont besoin les handicapés physiques. Il s'agit de fournir des ressources sur une base continue à ceux qui ont des problèmes de santé mentale et qui veulent procéder à des rénovations, par exemple, faire élargir les fenêtres, améliorer leur sécurité, contrôler le bruit et avoir accès à un logement plus près des services.*

*Seuls ceux qui louent leur logement ont droit à ce supplément, pas les propriétaires. Le locataire continue à y avoir droit quand il change de logement<sup>197</sup>.*

Les témoignages qu'il a entendus ont convaincu le Comité de la nécessité d'un investissement fédéral majeur dans le logement, à trois niveaux : augmentation de l'offre de logements, subventions d'aide au loyer et accroissement des services de soutien pour faciliter la vie dans la collectivité.

**Les témoignages qu'il a entendus ont convaincu le Comité de la nécessité d'un investissement fédéral majeur dans le logement: augmentation de l'offre de logements, subventions d'aide au loyer et accroissement des services de soutien pour faciliter la vie dans la collectivité.**

La construction de logements supervisés et la prestation de services de soutien additionnels touchent des secteurs qui relèvent du gouvernement fédéral et des provinces et territoires, mais la prestation des services de soutien est une responsabilité provinciale. Le Comité pense donc qu'il vaut mieux que le financement fédéral en la matière soit acheminé par le truchement du Fonds de transition qui sera administré par la Commission canadienne de la santé mentale. En conséquence, il recommande :

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**Que les services conçus pour permettre aux personnes atteintes de maladie mentale de vivre dans la société soient financés dans le contexte du volet Panier de services communautaires du Fonds de transition en santé mentale administré par la Commission canadienne de la santé mentale.**

Le Comité estime que les mesures afférentes aux deux niveaux d'intervention connexes précités (construction de nouveaux logements et offre de suppléments au loyer) devraient elles aussi être financées par l'intermédiaire du Fonds de transition, mais que, dans

<sup>197</sup> 2 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/17evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

l'administration du volet logement du Fonds, la Commission canadienne de la santé mentale devrait faire appel aux structures et organismes fédéraux qui s'occupent des programmes de logement abordable, comme la Société canadienne d'hypothèques et de logement.

Le Comité remarque avec intérêt que le ministre fédéral du Travail et du Logement a annoncé en mars 2005 que les programmes de supplément au loyer seraient désormais admissibles au financement accordé par le biais de l'Initiative en matière de logement abordable lancée pour financer la construction de logements abordables. Il estime opportun d'adopter une démarche similaire pour le financement, par le gouvernement fédéral, de mesures d'aide au logement à l'intention des personnes souffrant d'une maladie mentale.

En conséquence, le Comité recommande :

11	<p><b>Que, dans le contexte du Fonds de transition en santé mentale, le gouvernement du Canada lance une Initiative d'aide au logement pour la santé mentale afin de financer la construction de logements abordables et des programmes de suppléments au loyer pour donner aux personnes atteintes de maladie mentale les moyens de louer un appartement au taux du marché.</b></p> <ul style="list-style-type: none"> <li>• <b>Que, dans la gestion du volet logement du Fonds de transition en santé mentale, la Commission canadienne de la santé mentale travaille en étroite collaboration avec la Société canadienne d'hypothèques et de logement.</b></li> </ul>
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On trouvera au chapitre 16 des précisions sur la taille recommandée de l'Initiative d'aide au logement pour la santé mentale, de même que les sommes associées aux autres recommandations.

### 5.6.2 Le panier de services communautaires

Pour bien vivre dans la collectivité, les personnes atteintes d'une maladie mentale grave ont besoin non seulement d'un logement, mais aussi de nombreux services. Il est prouvé que les services décrits ci-dessous améliorent les conditions de vie des personnes concernées en leur permettant de mener une vie productive dans la société. Ils font partie des services que les gouvernements placent au cœur d'un système de santé mentale reposant principalement sur des services communautaires :

**Pour bien vivre dans la collectivité, les personnes atteintes d'une maladie mentale grave ont besoin non seulement d'un logement, mais aussi de nombreux services.**

**Ce sont les particularités de chaque collectivité qui devraient déterminer le contenu optimal du panier de services.**

- *des équipes de suivi intensif dans la collectivité* (ESIC) qui offrent des services complets continus de traitement, de réadaptation et de soutien aux personnes atteintes d'une maladie mentale grave qui présentent des besoins multiples et complexes

auxquels il est impossible de répondre avec un niveau d'intervention moins intensif;

- des *unités d'intervention d'urgence* accessibles et mobiles capables d'intervenir, 24 heures sur 24, sept jours sur sept, auprès des clients de tous âges;
- une *prise en charge intensive des cas* qui permet aux malades d'atteindre leurs objectifs en matière de traitement, de soutien et de rétablissement, d'opérer des changements positifs durables et de vivre dans la collectivité dans la plus grande autonomie possible.

Le Comité sait très bien que ces trois services ne sont pas les seuls qui devraient être financés à même le Fonds de transition en santé mentale. De nombreux autres pourraient être financés dans le contexte du panier de services communautaires comme des services précoces en cas de psychose, des services à l'intention des personnes atteintes d'une maladie mentale qui ont maille à partir avec la justice, des centres d'accueil, des services d'entraide, des programmes d'aide à l'emploi, des programmes pour troubles concomitants, des services axés sur les besoins des réfugiés et des immigrants sur le plan de la santé mentale, pour ne nommer que ceux-là. Cependant, comme on l'a dit ailleurs, ce sont les particularités de chaque collectivité qui devraient déterminer le contenu optimal du panier de services. En conséquence, la recommandation ci-dessous ne doit pas être interprétée comme une prescription; elle atteste implicitement la nécessité d'une certaine souplesse, exigeant simplement que les services soient offerts localement.

Le Comité recommande :

12	<p><b>Que soit financé à même le Fonds de transition en santé mentale un panier de services communautaires dont l'utilité, pour aider les personnes atteintes d'une maladie mentale, en particulier celles qui souffrent d'une maladie mentale grave et persistante, à mener une vie productive dans la société, a été démontrée.</b></p> <p><b>Que ce panier de services communautaires comprenne notamment des équipes de suivi intensif dans la collectivité, des unités d'intervention d'urgence et des programmes de prise en charge intensive des cas, et que la seule condition d'admissibilité au financement d'un service donné à même le Fonds de transition en santé mentale soit que le service soit offert dans la collectivité concernée.</b></p>
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On trouvera au chapitre 16 des précisions sur la taille recommandée du panier de services communautaires.

### 5.6.3 Promotion des soins en collaboration

La plupart des gens qui s'adressent à un professionnel pour un problème de santé mentale s'adressent d'abord à un médecin, et non à un psychologue, à un travailleur social ou à une autre personne. Cela tient principalement au nombre relativement plus grand de médecins et au mode de fonctionnement des systèmes publics d'assurance-maladie des provinces et des territoires — en général, seules les visites chez le médecin sont couvertes, et les services des autres professionnels de la santé mentale, comme les psychologues, sont à la charge du malade.

**Il est important d'encourager la collaboration dans le contexte de l'élaboration d'un éventail intégré de services communautaires.**

Le Comité estime important d'encourager la collaboration dans le contexte de l'élaboration d'un éventail intégré de services communautaires. La formule des soins en collaboration est la plus prometteuse si l'on veut améliorer l'accès aux soins et la qualité des soins et services de première ligne. Une récente étude américaine des traitements et services en santé mentale fondés sur l'expérience clinique a démontré le succès de cette formule :

[traduction] Par exemple, l'évaluation d'un modèle de soins en collaboration faisant appel à des spécialistes de la santé mentale autres que des médecins montre que les malades souffrant de dépression traités au moyen du modèle des soins en collaboration dans un contexte de soins primaires ont bénéficié d'une réduction sensiblement plus grande des symptômes après un an que les malades traités suivant la formule normale de soins primaires<sup>198</sup>.

L'idée des soins en collaboration constitue en quelque sorte le prolongement du principe du « partage des soins » élaboré pour promouvoir une meilleure collaboration entre les psychiatres et les omnipraticiens. Par les soins en collaboration, dans le sens où l'entend l'Initiative canadienne de collaboration en santé mentale (ICCSM), on cherche à élargir « le cadre de collaboration afin [d'inclure] une vaste gamme de fournisseurs de services de santé mentale, de consommateurs et de membres de la famille dans ces partenariats »<sup>199</sup>.

**Les soins en collaboration cherchent à élargir « le cadre de collaboration afin [d'inclure] une vaste gamme de fournisseurs de services de santé mentale, de consommateurs et de membres de la famille dans ces partenariats**

<sup>198</sup> A. Lehman, H. Goldman, L. Dixon, et R. Churchill, (juin 2004), *Evidence-based mental health treatments and services: Examples to inform public policy*, Milbank Memorial Fund, p. 14.

<sup>199</sup> Nick Kates (17 février 2005), témoignage devant le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/comm-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/comm-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47). L'Initiative canadienne de collaboration en santé mentale (ICCSM) est un regroupement de 12 organisations nationales représentant des services communautaires, des groupes de consommateurs, des familles et des groupes d'entraide, des diététiciens, des omnipraticiens, des infirmières, des ergothérapeutes, des pharmaciens, des psychologues, des psychiatres et des travailleurs sociaux financés à même le Fonds pour l'adaptation des soins de santé primaires. L'ICCSM est en train de mettre la dernière main à une série de 12 rapports sur les soins de santé mentale en collaboration au Canada et à l'étranger; avant que son financement expire en mars 2006, l'ICCSM a l'intention de publier des brochures visant à

Le président de l'ICCSM, le D<sup>r</sup> Nick Kates, a expliqué au Comité que :

*[...] ce genre d'intégration offre un certain nombre d'avantages. Tout d'abord, on augmente ainsi l'accès aux services de santé mentale pour un grand nombre de personnes qui, autrement, n'y auraient pas accès. Nous savons que 72 p. cent des personnes souffrant d'un problème de santé mentale ne reçoivent pas de soins pendant au moins un an, mais que 80 p. cent de ces personnes se rendent quand même chez leur médecin de famille<sup>200</sup>.*

Le D<sup>r</sup> Kates a décrit l'éventail des services qui pourraient être offerts dans le contexte de soins primaires, mentionnant notamment :

*[...] la détection précoce, la prévention et la promotion de la santé, les consultations, le traitement, le suivi et même certains services de réadaptation, mais nous insistons sur le fait qu'il faut voir comme complémentaires les systèmes de santé mentale et de soins primaires. L'un ne remplacera pas l'autre<sup>201</sup>.*

Il a ajouté :

*Nous voyons aussi les avantages de pharmaciens, diététistes, navigateurs de soins, programmes de soutien par les pairs, ainsi qu'une plus grande participation du consommateur et des membres de sa famille. Nous croyons en un modèle de soins axés sur le client. Nous pensons que les soins primaires sont idéalement placés pour le faire. Notre concept de soins axés sur le client inclut la création de plans de soins en collaboration, le consommateur étant un partenaire actif du traitement, le développement de mécanismes de soutien par les pairs et la participation du consommateur à tous les aspects de la planification, de la prestation et de l'évaluation des services de santé mentale en soins primaires<sup>202</sup>.*

Dans un document de l'ICCSM, on lit :

Il existe différentes façons de dispenser des services de santé mentale dans les contextes des soins de santé primaires, par exemple : dispenser les soins de santé mentale directement dans les contextes des soins de santé primaires ou fournir un soutien indirect en santé

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aider les malades et leur famille, les professionnels de la santé et les décisionnaires à comprendre les enjeux des soins en collaboration en santé mentale et à bien exploiter ce modèle.

<sup>200</sup> 17 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>201</sup> 17 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>202</sup> 17 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/07ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

mentale aux prestataires de soins de santé primaires dans les contextes de soins de santé primaires. Dans le premier cas, les soins de santé mentale sont dispensés par un spécialiste de la santé mentale; dans le second, les soins de santé mentale sont dispensés par un prestataire de soins de santé primaires qui reçoit le soutien ou qui consulte un spécialiste de la santé mentale<sup>203</sup>.

Et aussi :

Les soins de santé mentale axés sur la collaboration prennent place à l'intérieur de divers milieux qui incluent les centres de santé communautaires, les bureaux des prestataires de soins de santé primaires, la résidence d'un individu, les écoles, les établissements correctionnels ou des endroits communautaires, tels que les refuges. Ceci varie selon les besoins et préférences de l'individu et de la connaissance, la formation et les compétences des prestataires de soins. La collaboration peut s'appuyer sur une évaluation conjointe ou sur la prestation de soins où plusieurs prestataires de soins accompagnent l'utilisateur, les familles et les aidants naturels, lorsque cela convient, ou encore, cette collaboration peut se faire par le biais de communications par téléphone ou par écrit. Autrement dit, il n'est pas nécessaire que les prestataires de soins de santé soient au même endroit pour qu'une collaboration efficace ait lieu<sup>204</sup>.

Le financement de l'ICCSM expire en mars 2006. Le Comité estime que le travail amorcé par l'ICCSM doit se poursuivre sur deux plans et il recommande en conséquence :

13	<p><b>Que les initiatives de soins en collaboration soient admissibles à un financement par le biais du Fonds de transition en santé mentale.</b></p> <p><b>Que le Centre d'échange des connaissances qui doit être établi dans le cadre de la Commission canadienne de la santé mentale (voir le Chapitre 16) encourage activement l'application des pratiques exemplaires dans l'élaboration et la mise en œuvre des initiatives de soins en collaboration.</b></p>
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<sup>203</sup> M. Gagné (mars 2005), *Les soins de santé mentale axés sur la collaboration, de quoi s'agit-il?* Une introduction au Cadre de travail en soins de santé mentale axés sur la collaboration, rapport préparé pour l'Initiative canadienne de collaboration en santé mentale, Mississauga, Ontario, p. 5, <http://www.ccmhi.ca>.

<sup>204</sup> *Ibid.*, p. 4-5.

### 5.6.3.1 Ressources humaines

Dans son rapport final sur le système de soins actifs (hôpitaux et médecins)<sup>205</sup>, le Comité a mis en relief les pénuries généralisées de ressources humaines du système de soins de santé. Des renseignements anecdotiques semblent indiquer que les mêmes pénuries affecteront le secteur de la santé mentale. Dans tout le système de santé, le vieillissement des effectifs et l'allongement des périodes d'étude et de formation des nouveaux fournisseurs de soins entraîneront vraisemblablement une aggravation des pénuries dans les prochaines années.

**Il est manifeste que les pénuries de main-d'œuvre qui affectent le secteur de la santé en général toucheront aussi celui de la santé mentale.**

Le problème de ressources humaines soulevé durant les audiences du Comité recoupe la nécessité de favoriser l'adoption de modèles de soins en collaboration dans le domaine de la santé mentale. Il existe très peu de données précises sur les ressources humaines dans le domaine de la santé mentale, mais il est manifeste que les pénuries de main-d'œuvre qui affectent le secteur de la santé en général toucheront aussi celui de la santé mentale. On pourra y remédier entre autres en encourageant l'adoption de pratiques de soins en collaboration qui permettent une exploitation plus optimale des ressources humaines en santé mentale.

Malheureusement, les études les plus récentes sur les ressources humaines ne contiennent pas de ventilation des pénuries de main-d'œuvre dans le secteur de la santé mentale. On note cependant dans un rapport de l'ICIS sur les fournisseurs de soins de santé que, de toutes les professions réglementées, c'est chez les psychologues que l'âge moyen est le plus élevé<sup>206</sup>.

**L'absence de planification nationale des ressources humaines touche le secteur de la santé mentale tout autant que le reste du système de soins de santé.**

Le Symposium national sur les lacunes des services de santé mentale à l'intention des personnes âgées qui vivent dans un établissement de soins de longue durée (avril 2002) a conclu que les pénuries de personnel professionnel et non professionnel constituaient l'un des plus gros problèmes de la prestation de services de santé mentale dans le contexte de soins de longue durée<sup>207</sup>.

**On ne saurait trop insister sur l'importance d'augmenter les effectifs parmi tous les fournisseurs de services en santé mentale parce qu'un grand nombre de services essentiels au bien-être des personnes souffrant d'une maladie mentale ne relèvent pas du système de santé public.**

L'absence de planification nationale des ressources humaines touche le secteur de la santé mentale tout autant que le reste du système de soins de santé. Dans son rapport final

<sup>205</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (octobre 2002), *La santé des Canadiens — Le rôle du gouvernement fédéral*, Rapport final, vol. 6, Recommandations en vue d'une réforme.

<sup>206</sup> Institut canadien d'information sur la santé (nov. 2001), *Les dispensateurs de soins au Canada*, p. 31.

<sup>207</sup> Académie canadienne de psychiatrie gériatrique et Coalition canadienne pour la santé mentale des personnes âgées (juin 2003), mémoire au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 8.

d'octobre 2002, le Comité a formulé plusieurs recommandations visant à augmenter le nombre des professionnels de la santé. Si ces recommandations étaient mises en œuvre, le nombre des fournisseurs de soins dans le secteur de la santé mentale augmenterait aussi.

On ne saurait trop insister sur l'importance d'augmenter les effectifs parmi tous les fournisseurs de services en santé mentale parce qu'un grand nombre de services essentiels au bien-être des personnes souffrant d'une maladie mentale ne relèvent pas du système de santé public. Comme ailleurs dans le système de soins de santé, les pénuries de main-d'œuvre figurent parmi les facteurs qui contribuent le plus aux temps d'attente intolérables. Le Comité note que l'Association des psychiatres du Canada a récemment publié une liste des temps d'attente maximaux recommandés pour certaines maladies psychiatriques, initiative qui, selon lui, contribuera avec d'autres à faire en sorte que les personnes souffrant de maladie mentale soient soignées dans des délais acceptables<sup>208</sup>.

**Le gouvernement australien a lancé il y a trois ans un programme conçu pour faciliter la prestation de soins aux personnes souffrant d'une maladie mentale : les médecins de premier recours touchent une compensation financière qui leur permet de passer davantage de temps avec les malades qui éprouvent des problèmes de santé mentale. Il y aurait lieu d'encourager des initiatives similaires au Canada.**

La nécessité de faire davantage appel à des modèles de soins en collaboration fait ressortir plusieurs autres problèmes de ressources humaines particuliers au secteur de la santé mentale. La mise en œuvre généralisée d'initiatives de soins en collaboration en santé mentale dépendra dans une large mesure de l'allure générale du secteur des soins de santé (en particulier de la création d'équipes pluridisciplinaires de soins primaires). La lenteur de la réforme des soins primaires au Canada est particulièrement inquiétante.

Concrètement, en raison de la difficulté de la réforme des soins primaires, beaucoup d'omnipraticiens travaillant seuls continueront d'assurer le gros des soins de santé mentale de leurs malades. Or, chacun sait que le système de rémunération à l'acte des médecins décourage ceux-ci de passer avec leur malade tout le temps voulu pour les aider à régler leurs problèmes de santé mentale. Le Dr Richard Goldbloom, professeur de pédiatrie à l'Université Dalhousie, a dit au Comité :

*Actuellement, j'offre mes services en tant qu'expert-conseil. La plupart des enfants que je rencontre me sont recommandés par des médecins qui dispensent des soins primaires.*

*Ça ne m'a pas pris beaucoup de temps pour découvrir que la principale raison pour laquelle les médecins qui dispensent des soins primaires me recommandent ces enfants, c'est qu'ils se rendent compte qu'ils ne régleront pas le cas en dix minutes.*

*Sir William Osler a dit une fois que, lorsque les médecins parlent de questions de principe, ils pensent invariablement à l'argent. Nous sommes aux prises avec un problème pratique en santé mentale. En effet,*

<sup>208</sup> Association des psychiatres du Canada (mars 2006), Établissement de priorités sur les délais d'attente touchant les personnes souffrant d'une maladie mentale grave.

*les gens sont rémunérés selon le nombre de patients qu'ils reçoivent en consultation. Tant et aussi longtemps que ce sera le cas, on n'offrira pas beaucoup de soins en santé mentale dans le cadre des soins primaires*<sup>209</sup>.

M. Dermot Casey, secrétaire adjoint chargé des priorités sanitaires et de la prévention du suicide au ministère de la Santé et de la Vieillesse de l'Australie a parlé au Comité d'une mesure qui pourrait aider les omnipraticiens rémunérés à l'acte qui souhaitent être mieux en mesure d'aider leurs malades aux prises avec des troubles mentaux. Le gouvernement australien a lancé il y a trois ans un programme conçu pour faciliter la prestation de soins aux personnes souffrant d'une maladie mentale : les médecins de premier recours touchent une compensation financière qui leur permet de passer davantage de temps avec les malades qui éprouvent des problèmes de santé mentale. M. Casey a expliqué au Comité la genèse du programme et ses principales caractéristiques :

*On nous a dit que si vous êtes omnipraticien et que quelqu'un se présente à votre cabinet et que vous pensez que cette personne a un problème de santé mentale, vous restez silencieux, parce que si vous ouvrez le dialogue, vous serez encore là vingt ou trente minutes plus tard et, évidemment, le paiement à l'acte est le mode de traitement en vigueur. Nous les avons encouragés en leur disant que si cela prend vingt minutes, nous allons les payer davantage pour avoir consacré ce temps aux malades. À l'heure actuelle, environ 15 p. cent de notre main-d'oeuvre d'omnipraticien s'est inscrite à ce programme. Nous disposons donc de 3 500 omnipraticiens qui participent à ce programme et qui se reconnaissent comme des gens qui peuvent offrir un peu plus de soins en santé mentale et des soins un peu meilleurs. Il s'agit d'un nouveau programme*<sup>210</sup>.

Il y aurait lieu d'encourager des initiatives similaires au Canada. Les gouvernements des provinces et des territoires devraient travailler en étroite collaboration avec les associations médicales pour revoir les grilles de tarification de manière à rémunérer les médecins de premier recours qui passent plus de temps avec les malades qui souffrent de problèmes de santé mentale. Quelques provinces ont déjà fait quelques pas dans cette direction. Par exemple, au Nouveau-Brunswick, les omnipraticiens payés à l'acte peuvent également facturer, pour au plus quatre heures par jour, pour de la psychothérapie, du counselling auprès de patients ou

**Le Comité encourage donc fortement les gouvernements des provinces et des territoires à chercher à supprimer cet obstacle financier et à faciliter les mouvements de fournisseurs de services de santé mentale entre les établissements et les pratiques communautaires.**

<sup>209</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>210</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 2 — *Santé mentale, maladie mentale et toxicomanie : Politiques et programmes de certains pays en matière de santé mentale*, chapitre 1, p. 16, <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/rep-f/report2/repintnov04vol2-f.pdf>.

auprès des familles. Ils peuvent également être remboursés pour le temps passé sur des conférences de cas avec d'autres intervenants en santé mentale.

Une étude des ressources humaines réalisée par l'Initiative canadienne de collaboration en santé mentale a mis au jour un autre problème. L'ICCSM note dans son rapport que des « différences de rémunération s'observent principalement chez les prestataires qui passent d'un milieu de soins institutionnels à un milieu communautaire ou vice-versa »<sup>211</sup>; les personnes qui pratiquent en milieu communautaire sont moins bien payées que les autres. Le Comité estime que cette inégalité est malavisée et qu'elle risque de nuire au développement des services communautaires. Il encourage donc fortement les gouvernements des provinces et des territoires à chercher à supprimer cet obstacle financier et à faciliter les mouvements de fournisseurs de services de santé mentale entre les établissements et les pratiques communautaires.

## 5.7 AUTRES MESURES

### 5.7.1 Soutien des aidants naturels

Les parents jouent un rôle essentiel, et parfois crucial, dans le soin des personnes souffrant de maladie mentale. D'après certaines estimations, près de 60 p. cent des familles de personnes atteintes de maladie mentale grave assurent les soins primaires, et bénéficient généralement de peu de conseils, de soutien ou de répit<sup>212</sup>. Ces familles doivent en plus se charger d'innombrables démarches pour le compte de leur parent malade dans un système de santé mentale fragmenté.

Le Comité, conscient de la valeur et de l'importance des soins dispensés par ces aidants naturels, a invité ceux-ci à comparaître durant les audiences publiques qu'il a tenues dans toutes les provinces et tous les territoires. Nous exposons leurs préoccupations au chapitre 2 et avons cherché à y répondre. À cet égard, nous abordons deux sujets clés dans le présent rapport : le soutien du revenu et les services de relève.

#### 5.7.1.1 Soutien du revenu

Le dévouement des aidants naturels a des conséquences financières. Ces personnes doivent par exemple souvent prendre congé pour s'occuper d'un parent malade. À ce sujet, le D<sup>r</sup> Kellie LeDrew, directeur des services cliniques du Newfoundland and Labrador Early Psychosis Program, a dit :

**Les aidants naturels devraient toucher une forme d'aide financière du gouvernement quand ils doivent s'absenter temporairement du travail pour s'occuper d'un parent souffrant de maladie mentale.**

*Nous sous-estimons parfois ce que la maladie mentale d'un des membres de la famille signifie pour l'ensemble de la famille. Il arrive souvent que*

<sup>211</sup> C. Bosco (septembre 2005), *Ressources humaines dans le domaine de la santé en soins de santé mentale axés sur la collaboration*, rapport préparé pour l'Initiative canadienne de collaboration en santé mentale, Mississauga, Ontario, p.8.

<sup>212</sup> Toronto-Peel Mental Health Implementation Task Force, (décembre 2002), *The Time Has Come: Make It Happen. A mental health action plan for Toronto and Peel*, p. xv.

*la mère se soit absentée de son travail. J'ai souvent dû donner des notes à des mères qui devaient justifier leur absence du travail et qui étaient restées à la maison pour que leur fils n'ait pas à être hospitalisé. Ces mères ne veulent pas quitter leur fils parce qu'elles craignent qu'il lui arrive quelque chose*<sup>213</sup>.

Le Comité estime que les aidants naturels devraient toucher une forme d'aide financière du gouvernement quand ils doivent s'absenter temporairement du travail pour s'occuper d'un parent souffrant de maladie mentale. Plusieurs raisons impérieuses nous confortent dans notre conviction :

- Il est avantageux pour les *personnes atteintes de maladie mentale* d'être soignées par une personne qui leur est familière, hors du cadre institutionnel. Ce type de soutien peut par ailleurs leur éviter des démêlés avec la justice ou l'itinérance.
- Les *aidants* peuvent ainsi conserver leur emploi tout en étant en mesure d'accompagner leur parent malade.
- Les *employeurs* peuvent conserver leur employé et éviter les coûts associés aux autres congés (comme les congés de maladie) auxquels un salarié peut faire appel quand il ne peut pas se prévaloir d'un congé pour le soin d'un membre de la famille ou que celui-ci est trop court.
- Les *gouvernements* y gagnent du fait que les aidants demeurent actifs et que les personnes atteintes de maladie mentale ne se retrouvent pas à l'hôpital, dans un établissement de soins de longue durée, en prison ou dans la rue, ce qui représente une économie pour le Trésor.

Le Régime d'assurance-emploi offre certes des prestations de compassion, mais elles sont réservées aux personnes qui prennent congé pour s'occuper d'un membre de leur famille gravement malade qui risque de mourir dans les six mois<sup>214</sup>. Il semblerait que ces prestations sont sous-utilisées, au moins en partie du fait des conditions d'admissibilité extrêmement restrictives.

Compte tenu de l'excédent considérable du compte d'assurance-emploi<sup>215</sup> et de la récente décision de la Cour suprême du Canada<sup>216</sup> affirmant le pouvoir constitutionnel du Parlement d'adapter le régime d'assurance-emploi aux réalités contemporaines, le Comité estime

<sup>213</sup> 15 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22evb-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>214</sup> Pour une explication détaillée, voir Assurance-emploi et prestations de compassion, [http://www.hrsdc.gc.ca/asp/passerelle.asp?hr=fr/ae/genres/prestations\\_compassion.shtml&chs=tyt#Qui](http://www.hrsdc.gc.ca/asp/passerelle.asp?hr=fr/ae/genres/prestations_compassion.shtml&chs=tyt#Qui).

<sup>215</sup> Dans son rapport de novembre 2004, la vérificatrice générale a indiqué que l'excédent cumulé du compte d'assurance-emploi atteignait 46 milliards de dollars. Voir Bureau du vérificateur général du Canada, *Rapport de novembre 2004*, chapitre 8, <http://www.oag-bvg.gc.ca/domino/rapports.nsf/html/20041108cf.html>.

<sup>216</sup> *Renvoi relatif à la Loi sur l'assurance-emploi (Can)*, art. 22 et 23, 2005 CSC 56, <http://www.lexum.umontreal.ca/csc-scc/en/rec/html/2005scc056.wpd.html>.

opportun d'élargir l'admissibilité aux prestations de compassion. En conséquence, il recommande :

- |    |  |
|----|--|
| 14 | <p>Que des prestations de compassion soient offertes pendant au plus six semaines à l'intérieur d'une période de deux ans à toute personne qui prend congé pour s'occuper d'un membre de sa famille atteint d'une maladie mentale qui risque l'hospitalisation, le placement dans un établissement de soins de longue durée, l'emprisonnement ou l'itinérance dans les six mois.</p> <p>Que l'admissibilité aux prestations de compassion soit déterminée sur recommandation de professionnels de la santé mentale et que leur paiement échappe au délai de carence habituel de deux semaines.</p> |
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#### 5.7.1.2 Services de relève

S'occuper d'une personne apparentée souffrant d'une maladie mentale est extrêmement exigeant, et les aidants risquent l'épuisement. Brenda McPherson, coordonnatrice provinciale du Psychiatric Patient Advocate Services au Nouveau-Brunswick a dit :

**Le Comité estime important d'améliorer considérablement les services de relève offerts aux familles pour éviter l'épuisement des aidants naturels.**

*[...] beaucoup des parents ou des soignants de ces patients sont littéralement épuisés. Ils prennent soin de ces personnes depuis qu'elles ont l'âge de 12, 13 ou 14 ans. Les soignants sont passés par toutes les étapes du système judiciaire, ils ont connu le système des foyers d'accueil, etc. Quand leurs enfants ont 25 ou 30 ans, ce sont de jeunes adultes qui sont parfois peu fonctionnels et à ce moment-là, ces soignants naturels sont totalement épuisés et ont accès à peu ou pas du tout de ressources. Voilà pourquoi j'estime que le gouvernement fédéral a un rôle important à jouer; il doit s'associer au gouvernement provincial pour améliorer les services et les ressources dont dispose la province<sup>217</sup>.*

Le Comité estime important d'améliorer considérablement les services de relève offerts aux familles pour éviter l'épuisement des aidants naturels. Plusieurs solutions ont été proposées, notamment les suivantes :

- visites à domicile d'une infirmière de santé publique pour offrir information et soutien aux familles de personnes récemment diagnostiquées<sup>218</sup>;

<sup>217</sup> 11 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evf-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evf-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>218</sup> Doris Ray, 6 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/18eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

- services de relève à domicile pour que les aidants puissent, par exemple, se rendre à un rendez-vous chez le médecin, assister à une réunion d'un groupe d'entraide ou aller faire des courses<sup>219</sup>;
- centres d'accueil de jour pour adultes<sup>220</sup>;
- amélioration des services de prise en pension temporaire : allongement de la période de répit et augmentation de la fréquence<sup>221</sup>.

Compte tenu des besoins variés des aidants naturels et de leur évolution dans le temps, il serait logique d'offrir diverses formules de services de relève. En conséquence, le Comité recommande :

15	<b>Que les mesures prises pour offrir aux aidants naturels davantage de services de relève adaptés aux besoins changeants des clients soient financées par la voie du Fonds de transition en santé mentale.</b>
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<sup>219</sup> Menna MacIssac, 10 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evd-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evd-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>220</sup> Christine Davis, 20 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/13eva-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

<sup>221</sup> Penny MacCourt, 8 June 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/20ev-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

### 6.1 INTRODUCTION

*Ce que je déplore le plus dans le travail en cours, c'est que personne n'insiste sur le fait que la plupart des troubles de santé mentale dont souffrent les Canadiens aujourd'hui ont débuté dans l'enfance ou l'adolescence. Faute de reconnaître cette réalité, nous devons traiter un cancer de phase quatre, souvent avec d'importants effets secondaires, plutôt qu'une maladie de phase un ou deux. Comme l'obésité, les questions de santé mentale, si elles ne sont pas traitées dans l'enfance, menacent de mener à la ruine notre système de soins de santé. — Diane Sacks<sup>222</sup>*

De très nombreux enfants et adolescents sont atteints de maladie mentale. Selon des estimations prudentes, au Canada jusqu'à 15 p. cent<sup>223</sup> d'entre eux sont touchés, soit un total d'environ 1,2 million de jeunes aux prises avec l'anxiété, la déficience de l'attention, la dépression, la toxicomanie et d'autres troubles<sup>224</sup>. L'incidence de cette situation est d'autant plus vive que, d'habitude, ces jeunes comptent sur leur famille pour s'occuper d'eux et les soutenir. Or, quand un enfant ou un adolescent est atteint d'une maladie mentale ou d'une toxicomanie, les soignants membres de sa famille souffrent aussi.

**Un total d'environ 1,2 million de jeunes sont aux prises avec l'anxiété, la déficience de l'attention, la dépression, la toxicomanie et d'autres troubles.**

Cette forte prévalence et l'existence de défenseurs tout à fait disposés à intervenir (c'est-à-dire les parents) auraient dû, pourrait-on penser, entraîner l'établissement d'un système de santé mentale bien organisé et suffisamment financé, capable de répondre aux besoins des enfants et des adolescents; pourtant, il n'en est rien. Le Comité a appris des témoins que le système est fragmenté et sous-financé, que les interventions se font longuement attendre, qu'il y a un manque criant de professionnels de la santé mentale et que les jeunes et leurs familles ne sont pas invités à participer à l'application de solutions viables à long terme afin de régler ces graves problèmes de santé mentale.

Les enfants et les adolescents sont considérablement défavorisés par rapport aux autres groupes démographiques souffrant de maladie mentale, car les lacunes du système les affectent de façon plus aiguë et plus grave. Le Comité juge essentiel d'agir énergiquement afin de s'attaquer dès maintenant aux problèmes de premier plan, quitte à apporter d'autres changements par la suite.

<sup>222</sup> 20 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47)

<sup>223</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie: Aperçu des politiques et des programmes au Canada*, chapitre 5, section 5.1.2, p. 95.

<sup>224</sup> *Ibid.*, p. 95-96.

## 6.2 INTERVENTION PRÉCOCE

On ne saurait assez insister sur l'importance d'une intervention précoce. Quand les symptômes de détresse ou de maladie font leur première apparition chez un enfant ou un adolescent, quel que soit son âge, la famille, les professionnels de la santé et les enseignants devraient intervenir immédiatement.

De plus, toutes ces interventions doivent se poursuivre, au besoin, lors du passage au milieu scolaire et, par la suite, à l'âge adulte. Le Comité partage les vues du D<sup>r</sup> Ian Manion, psychologue, qui a insisté sur l'importance d'intervenir auprès des enfants et des adolescents à toutes les étapes de leur développement :

**On ne saurait assez insister sur l'importance d'une intervention précoce.**

*Si on s'attache uniquement à un aspect, on crée encore un cloisonnement. Vous avancez que c'est là que l'argent devrait être affecté, et cela signifie qu'une génération d'enfants plus âgés et de jeunes en ressortent perdants, ou qu'une génération d'adolescents en ressortent perdants. Bien sûr, si on perd une génération d'adolescents, on perd également la prochaine génération de parents, ceux qui seront responsables, plus tard, d'enfants âgés de moins de trois ans. Par conséquent, il faut envisager de façon globale le continuum de soins, et l'appliquer à toutes les étapes du développement<sup>225</sup>.*

La maladie mentale et la toxicomanie ne connaissent pas de limites d'âge arbitraires. Voilà pourquoi le Comité ne préconise pas que le financement des services de santé mentale pour les enfants et les adolescents cible des tranches d'âge précises. Nous proposons plutôt l'établissement d'une gamme complète de services pleinement intégrés visant l'enfance, l'adolescence et l'âge adulte.

**Nous suggérerons de ne plus interrompre les services sociaux ou de santé mentale quand le client atteint un âge fixé d'avance après quoi ce dernier est censé chercher de l'aide auprès du système pour les adultes.**

De plus, nous suggérerons de ne plus interrompre les services sociaux ou de santé mentale — qui sont *tous les deux* importants pour la santé mentale — quand le client atteint un âge fixé d'avance (par exemple 16 ou 18 ans), après quoi ce dernier est censé chercher de l'aide auprès du système pour les adultes.

### 6.2.1 Les années préscolaires

Une bonne partie des témoignages que le Comité a entendus insiste sur l'importance d'une intervention précoce, mais principalement auprès des enfants d'âge scolaire. S'il est vrai qu'il est à la fois logique et commode que les interventions en santé mentale se déroulent dans le cadre du système d'éducation, il reste qu'il ne faut pas fermer les yeux sur le fait que les

<sup>225</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

problèmes peuvent survenir avant l'entrée à l'école; c'est d'ailleurs ce qui se produit souvent. Comme l'a expliqué Sharon Steinhauer, membre de l'Alberta Mental Health Board :

*Nous savons que les facteurs de risque proviennent des genres de milieu familial et communautaire dans lesquels vivent ces enfants [...] La question est la suivante : Disposons-nous de mécanismes d'identification des enfants qui sont à risque et disposons-nous de moyens de les intégrer au réseau de soutien de façon à pouvoir, en définitive, atténuer certains des risques qui font que leur famille est vulnérable?*

*Les enfants sont élevés d'abord par la famille, et deuxièmement à l'école. Ainsi, ces premières années, que visent les stratégies du jeune enfant, correspondent à la période préscolaire. Nous recourons au programme Bon départ et à d'autres mécanismes pour tenter d'identifier les enfants ayant peut-être besoin de plus de soutien que ce qui leur est naturellement fourni<sup>226</sup>.*

Quand les enfants vieillissent, leurs problèmes naissants de santé mentale les suivent dans le milieu scolaire. Michelle Forge, surintendante des services aux étudiants à la Commission scolaire du district de Bluewater, souligne que :

*Quand ils [franchiront la porte de l'école], ils seront mieux préparés, car un enseignant les aura aidés à comprendre ce qu'est l'école, et à faire cette transition. Cela aide également l'équipe responsable des enfants d'âge préscolaire à naviguer dans le système. Nous formons un système, et il est très différent des systèmes qu'on trouve ailleurs. Nous en sommes conscients, et nous devons fournir les outils de navigation et les gens nécessaires pour faire cela<sup>227</sup>.*

Les années préscolaires présentent deux défis : le premier consiste à reconnaître les enfants qui sont atteints d'une maladie mentale ou qui risquent d'en développer une, et de leur fournir des services. Le second concerne la gestion efficace du passage de la petite enfance (de 0 à 5 ans) au système scolaire. Le Comité recommande :

16

**Que les conseils et les commissions scolaires rendent obligatoire la mise sur pied d'équipes en milieu scolaire composées de travailleurs sociaux, de travailleurs auprès des jeunes et d'enseignants afin d'aider les aidants familiaux à trouver les services de santé mentale dont leurs enfants et leurs adolescents ont besoin et que ces équipes fassent appel à la panoplie de traitements qu'offrent les diverses disciplines.**

<sup>226</sup> 9 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/21eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/21eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>227</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

## 6.2.2 Les enfants d'âge scolaire

De nombreux témoins ont réclamé que les écoles soient mieux outillées pour traiter des questions de santé mentale chez les enfants. Le D<sup>r</sup> Richard Goldbloom, professeur en pédiatrie, est même allé jusqu'à dire que : « Je considère que l'école est le centre de soins de santé le plus sous-exploité de n'importe quel centre au pays<sup>228</sup>. » Il a ajouté que :

**De nombreux témoins ont réclamé que les écoles soient mieux outillées pour traiter des questions de santé mentale chez les enfants.**

*[N]ous devons effectuer un déménagement majeur. Les services de santé mentale dans la plupart des collectivités doivent déménager dans les écoles. L'école est l'habitat naturel des enfants. Ils y vivent pendant six ou huit heures par jour, les parents y vont souvent, et c'est là qu'on peut régler les problèmes en collaborant avec les enseignants<sup>229</sup>.*

Le D<sup>r</sup> John Service, président de la Canadian Alliance on Mental Illness and Mental Health, a abondé dans le même sens :

*Si nous ne prenons qu'un seul groupe, c'est-à-dire les jeunes adultes, et que nous demandons à ces derniers pourquoi ils n'ont pas recours aux services de santé mentale, ils répondront très souvent que c'est parce que ces services se trouvent dans les grands hôpitaux, c'est-à-dire dans des endroits où ils ne se sentent pas à l'aise. [...] L'endroit où nous offrons nos services signifie que parfois on ne s'en servira pas de façon très efficace. C'est une question sérieuse. [...]*

*Après 15 ans de pratique comme psychologue auprès d'enfants, d'adolescents et de familles en Nouvelle-Écosse, je peux vous dire que nous avons des problèmes à faire en sorte que les enfants et leurs familles se sentent à l'aise en milieu hospitalier. Nous avons négocié un accord avec la commission scolaire du comté pour offrir nos services de santé mentale dans les écoles. C'était beaucoup plus efficace. Les gens se sentaient beaucoup plus à l'aise et nous avons aussi accès aux professeurs<sup>230</sup>.*

Un consensus s'est également dégagé sur l'importance pour les enseignants d'avoir la formation nécessaire afin de mieux reconnaître les problèmes de santé mentale chez leurs

<sup>228</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>229</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>230</sup> 21 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

élèves et de les aider à trouver un traitement efficace, plutôt que d'aiguiller leurs élèves vers des salles d'urgence déjà surchargées ou de les inscrire sur de longues listes d'attente, comme ils le font actuellement.

La D<sup>re</sup> Mimi Israël, psychiatre en chef à l'Hôpital Douglas (Montréal), réclame une injection de fonds dans la formation de professionnels — dont des enseignants — qui œuvrent dans des domaines autres que la santé mentale. En fait, selon elle, « nous devrions élaborer un programme d'études en santé mentale qui s'enchâsserait dans le programme pédagogique des enseignants, des techniciens en garderie et d'autres professionnels de la santé<sup>231</sup> ».

Mme Judy Hills, directrice exécutive de la Fondation canadienne de la recherche en psychiatrie, a décrit un projet que son organisme a entrepris parce que « la recherche montre que l'enseignant est la première personne à qui les jeunes s'adressent en vue d'obtenir de l'aide<sup>232</sup> ». Elle a souligné que :

**Le Comité insiste sur l'importance pour les enseignants d'avoir la formation nécessaire afin de mieux reconnaître les problèmes de santé mentale chez leurs élèves et de les aider à trouver un traitement efficace**

*[L]es enseignants éprouvaient de la difficulté à composer avec l'évolution rapide des choses [dans le système scolaire]. Ils nous ont demandé si nous pourrions élaborer un guide pour les aider jusqu'à ce qu'ils trouvent de l'aide pour les enfants avec lesquels ils travaillent. Les enfants de leurs classes [devaient attendre] jusqu'à un an et demi pour des renvois à des services.*

*La fondation a constitué un groupe d'experts du domaine de l'éducation. Nous avons des directeurs, des enseignants, des éducateurs spécialisés et des jeunes, et ces personnes ont participé à l'élaboration d'un guide intitulé « Quand ça ne va pas »<sup>233</sup>.*

Mme Hills a ajouté quelques précisions :

*Nous savons que les enseignants ne peuvent établir un diagnostic, et nous ne voulons pas qu'ils le fassent, mais nous voulons les aider à acquérir certaines compétences au chapitre du repérage précoce et à comprendre certains des troubles de l'humeur et du comportement qui pourraient être causés par des troubles mentaux. Cela leur procure une base leur permettant d'aller de l'avant<sup>234</sup>.*

<sup>231</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>232</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>233</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>234</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Plusieurs mesures indispensables doivent être prises afin que l'école devienne un lieu privilégié pour la prestation efficace des services de santé mentale. Premièrement, son potentiel doit être reconnu. Deuxièmement, les services hospitaliers ou communautaires doivent être transférés à l'école ou alors de nouveaux services doivent y être établis. Troisièmement, il faut donner aux enseignants le temps et les ressources nécessaires pour jouer ce nouveau rôle qui exige une plus grande implication. Par conséquent, le Comité recommande :

**Plusieurs mesures indispensables doivent être prises afin que l'école devienne un lieu privilégié pour la prestation efficace des services de santé mentale.**

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|----|---|
| 17 | <p><b>Que des services de santé mentale destinés aux enfants et aux adolescents soient fournis en milieu scolaire par des équipes constituées sur place, comme le recommande la section 6.2.1 ci-dessus.</b></p> <p><b>Que les enseignants reçoivent une formation sur la détection précoce de la maladie mentale.</b></p> <p><b>Que l'on accorde aux enseignants le temps voulu et les ressources et le soutien concrets nécessaires pour jouer ce nouveau rôle.</b></p> |
|----|---|

#### **6.2.2.1 Dépistage de la maladie mentale**

Certains ont suggéré au Comité de confier un nouveau rôle aux écoles, soit l'administration de tests de dépistage de la maladie mentale. Cette proposition suscite une certaine controverse. Ainsi, Mme Carolyn Mayeur, lorsqu'elle a témoigné devant le Comité pour raconter ce que sa fille a vécu, s'est prononcée en faveur de programmes généraux de dépistage :

*Je crois qu'on devrait effectuer régulièrement des évaluations psychologiques dans toutes les classes. Danielle souffrait d'un déséquilibre chimique qui est apparu lorsqu'elle était très jeune, mais il n'y avait aucun mécanisme de dépistage. Nous aurions peut-être pu éviter beaucoup de choses si nous l'avions repéré plus tôt<sup>235</sup>.*

D'autres, dont la Dre Diane Sacks, présidente sortante de la Société canadienne de pédiatrie, prônent une approche plus ciblée :

*Il est positif de reconnaître qu'il faut offrir les services en milieu scolaire. L'étape suivante consiste à reconnaître qu'il existe maintenant des outils peu coûteux, faciles à utiliser et déjà validés pour dépister nombre de ces troubles chez les enfants. Ces outils doivent être utilisés auprès d'une*

<sup>235</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*population à haut risque, qu'il est possible de définir dans le système scolaire.*

*Qui compose cette population? Ce sont les enfants souvent absents, ceux qui échouent ou qui décrochent. Il faut les repérer et vérifier automatiquement leur état de santé mentale. Il n'est pas nécessaire d'attendre qu'ils soient en prison pour les tester et constater, comme cela s'est fait aux États-Unis, que près de 80 p. cent des détenus sont atteints d'une maladie qui aurait pu être diagnostiquée<sup>236</sup>.*

Le D<sup>r</sup> Norman Hoffman, directeur des Services de santé mentale pour étudiants de l'Université McGill, s'est montré plus prudent. Selon lui :

**Bien que fermement convaincus de l'importance d'un diagnostic précoce, nous sommes soucieux des obstacles pouvant nuire à la mise en œuvre de tels programmes dans les écoles.**

*La tendance est au diagnostic rapide. Les programmes de dépistage comme celui de la dépression peuvent sensibiliser aux problèmes de la dépression, mais trop souvent, leur seul effet est de répandre l'idée selon laquelle la dépression serait une entité biologique particulière. C'est ce que prône l'industrie pharmaceutique, sans la moindre confirmation des milieux scientifiques.*

*L'humeur dépressive est un problème complexe. Il y a vingt ans, les étudiants nous consultaient et disaient : « Je me sens déprimé, abattu. » Aujourd'hui, ils disent : « Je crois que je fais une dépression ». Nous disons : « Que voulez-vous dire? Comment sentez-vous? Que se passe-t-il dans votre vie? » Ils répondent : « Non, je fais une dépression. » Les gens veulent des réponses rapides et des solutions rapides, mais cela ne donne rien<sup>237</sup>.*

Il a ensuite proposé une solution de rechange aux programmes généraux de dépistage :

*En venant en aide aux familles à faible revenu en diminuant le nombre d'élèves par classe pour que les enseignants aient le temps de connaître leurs élèves. Parce que si les enseignants connaissent leurs élèves, alors il est inutile de faire un test de dépistage de dépression. Les professeurs sauront qui a des problèmes<sup>238</sup>.*

Le Comité est bien conscient de l'appui dont bénéficient les divers programmes de dépistage. Bien que fermement convaincus de l'importance d'un diagnostic précoce, nous sommes

<sup>236</sup> 20 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>237</sup> 21 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>238</sup> 21 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

soucieux non seulement des critiques formulées, mais aussi des obstacles pouvant nuire à la mise en œuvre de tels programmes dans les écoles. Ces obstacles se divisent en deux grandes catégories.

#### 6.2.2.1.1 Obstacles d'ordre juridique

Comme nous l'avons souligné à la section 4 du chapitre 4, les services de santé mentale relèvent principalement des provinces et des territoires; par conséquent la collaboration de ces dernières sera essentielle à la mise en œuvre d'une éventuelle stratégie nationale de dépistage de la maladie mentale. De plus, il faudra respecter les lois de chaque compétence concernant la prestation de services de santé en milieu scolaire, le consentement aux soins médicaux, la nature confidentielle des renseignements personnels et l'hospitalisation d'un élève pour traiter une maladie donnée.

**Le Comité estime que pour effectuer le dépistage des éventuels problèmes de santé mentale chez les élèves, il faudra au préalable obtenir un consentement éclairé**

Le Comité estime que pour effectuer le dépistage des éventuels problèmes de santé mentale chez les élèves, il faudra au préalable obtenir un consentement éclairé, même si ce dépistage ne figure pas parmi les services médicaux nécessitant un consentement en vertu des dispositions législatives provinciales et territoriales applicables. Il faudrait donc obtenir le consentement soit de l'élève, soit des soignants membres de sa famille, selon la situation.

L'âge auquel une personne est considérée apte à consentir à un traitement ou à le refuser varie selon les provinces et les territoires. Cependant, quoi qu'en dise la loi, l'âge n'est pas un facteur déterminant : une personne qui est mineure ou qui n'a pas l'âge prévu par la loi peut très bien être capable de consentir à un traitement médical si elle en comprend la nature et les conséquences.

Pour qu'un consentement soit valide, il doit être donné en toute liberté et en toute connaissance de cause, ce qui veut dire que l'intéressé doit être bien informé de la nature, de la gravité et des risques d'un dépistage de maladie mentale. Il a aussi droit à des réponses claires à ses questions au sujet du procédé ou du processus. Il peut s'avérer particulièrement important d'exiger que le consentement soit accordé sans influence induite et sans recours à la force dans les cas où un élève, qui n'a pas encore atteint l'âge requis pour consentir, est prié d'accepter un dépistage de maladie mentale alors qu'il est en présence de dirigeants d'école, de professionnels de la santé et de pairs.

Si des tests de dépistage de la maladie mentale sont administrés à l'école, des mesures devront être prises pour protéger la confidentialité des renseignements personnels de chaque élève. De plus, si un élève est compétent et apte à accorder lui-même son consentement, une question de nature juridique se pose, à savoir si le dépistage et ses résultats peuvent être divulgués à la famille de l'élève. La loi n'est pas la même d'un bout à l'autre du Canada. Diverses situations peuvent donc se présenter : il peut y avoir, selon les cas, interdiction, permission ou obligation de communiquer à la famille l'information sur l'état de santé de l'élève et les soins qui lui sont dispensés.

Un traitement qui fait suite aux résultats du dépistage sera aussi assujéti à d'importantes considérations juridiques. Les dispositions touchant le consentement et la confidentialité de l'information continueront de s'appliquer, mais celles s'appliquant au traitement ne seront

pas nécessairement les mêmes qu'au moment du dépistage. Le traitement de la maladie mentale est une question aux conséquences plus graves que l'évaluation; il est donc possible qu'une personne capable de consentir à un dépistage et à la divulgation des résultats ne soit pas apte à consentir à un traitement ou à interdire que des tiers (par exemple la famille) soient informés des diverses options de traitement.

#### 6.2.2.1.2 Obstacles d'ordre pratique

Non seulement y a-t-il incompatibilité des lois en matière de dépistage de la maladie mentale, mais il y a aussi lieu de se demander ce que les administrations scolaires ou les soignants membres de la famille feront de l'information que pourrait révéler le dépistage. À l'heure actuelle, seul un faible pourcentage de personnes aux prises avec une maladie mentale ou une toxicomanie, enfants ou adultes, consulte un professionnel de la santé<sup>239</sup>. Et pourtant, le système est déjà surchargé.

**Il est peu probable que nous disposions prochainement d'un nombre suffisant de professionnels de la santé mentale pour aider ces enfants et adolescents. Dans ces circonstances, le dépistage ne sera d'aucune utilité et risque même de causer du tort**

Si des tests de dépistage de maladie mentale sont administrés à grande échelle dans les écoles, il faudra raisonnablement s'attendre à ce que la maladie mentale soit diagnostiquée chez un plus grand nombre d'enfants et d'adolescents. Carole Tooton, directrice exécutive de l'Association canadienne pour la santé mentale, Division de la Nouvelle-Écosse, a mis le Comité en garde :

*Actuellement, nous hésitons quelque peu à donner des conférences dans les écoles. Nous recevons beaucoup d'appels, surtout de classes de 11<sup>e</sup> année, dont une partie du programme d'études traite de psychologie. Nous craignons que, après notre exposé, l'école ne mette pas en place de système pour régler les problèmes qui pourraient survenir à l'issue de la conférence. Nous devons savoir que les enseignants et les orienteurs disposent d'une stratégie appropriée pour traiter avec un étudiant qui réalise qu'il pourrait souffrir d'un problème de dépression ou qui a des pensées suicidaires.*

*Nous sommes hésitants parce que nous savons qu'une stratégie de suivi appropriée est essentielle à la réussite de notre programme. Si l'école n'a pas de stratégie, elle a du mal à trouver les bons professionnels dans le système<sup>240</sup>.*

De plus, même si la stratégie voulue est en place, il reste que, pour des raisons dont il est question à la section 6.3 du présent chapitre, il est peu probable que nous disposions

<sup>239</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 8, section 8.2.6, p. 180.

<sup>240</sup> 9 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

prochainement d'un nombre suffisant de professionnels de la santé mentale pour aider ces enfants et adolescents. Dans ces circonstances, le dépistage ne sera d'aucune utilité et risque même de causer du tort.

En résumé, même si le Comité estime que le dépistage de la maladie mentale dans les écoles peut offrir certains avantages, deux motifs militent contre l'établissement d'un programme de dépistage à grande échelle à l'heure actuelle. En premier lieu, une stratégie nationale sera tout à fait impraticable étant donné l'incompatibilité des dispositions législatives provinciales et territoriales actuelles; malheureusement, on ne constate pour l'instant aucune volonté d'entreprendre la profonde réforme législative qui serait nécessaire pour éliminer ces incompatibilités.

En deuxième lieu, s'il est vrai que des mesures ciblant des groupes particuliers de la population étudiante soient prometteuses, il reste que l'actuelle pénurie de professionnels de la santé constitue toujours un obstacle de taille.

Peut-être, lorsque le système de santé mentale aura subi une réforme permettant d'améliorer sa capacité et son efficacité, pourra-t-on envisager d'appliquer certains programmes circonscrits de dépistage dans certaines compétences.

#### ***6.2.2.2 Stigmatisation et discrimination***

La question de la stigmatisation et de la discrimination revient tout au long du rapport et fait l'objet d'un examen plus détaillé au chapitre 16<sup>241</sup>. Néanmoins, le Comité tient à souligner de nouveau l'importance de commencer très tôt à appliquer dans les écoles les mesures d'information et de sensibilisation au sujet de la maladie mentale.

La stigmatisation est souvent le résultat de l'ignorance. Or, les Canadiens savent peu de choses sur la maladie mentale. Les raisons qui militent en faveur de programmes de sensibilisation visant les jeunes sont simples. Comme le souligne le D<sup>r</sup> Simon Davidson, chef de la psychiatrie au Centre hospitalier pour enfants de l'Est de l'Ontario, « nous avons constaté que c'est assez facile d'amener les jeunes à ne plus stigmatiser tout ce qui touche la santé mentale. Je ne crois pas qu'on puisse dire la même chose des adultes<sup>242</sup> ».

Bref, quand les ressources sont rares, il est préférable que l'information vise ceux qui y sont le plus réceptifs. Par conséquent, le Comité recommande :

**Nous avons constaté que c'est assez facile d'amener les jeunes à ne plus stigmatiser tout ce qui touche la santé mentale. Je ne crois pas qu'on puisse dire la même chose des adultes. Quand les ressources sont rares, il est préférable que l'information vise ceux qui y sont le plus réceptifs.**

<sup>241</sup> Le lecteur trouvera un examen complet de la question de la stigmatisation et de la discrimination dans : Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 3.

<sup>242</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

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- 18 **Que les élèves soient informés à l'école au sujet de la maladie mentale et de sa prévention et que la Commission canadienne de la santé mentale (voir le Chapitre 16) travaille en étroite collaboration avec les éducateurs pour mener des campagnes de sensibilisation ciblées visant à réduire la stigmatisation et la discrimination.**
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### 6.2.3 Après l'école — Le passage au système pour adultes

Comme nous l'avons dit précédemment dans ce chapitre, aucune date limite ne s'applique à la maladie mentale. Or, on ne peut pas en dire autant des services sociaux et de santé mentale à l'intention des enfants et des adolescents. Le Comité estime que ce problème fort répandu *ne doit pas perdurer*.

#### 6.2.3.1 Services de santé mentale

La brusque interruption des services essentiels a été comparée par certains, à juste titre, à l'impression de tomber d'une falaise. Et pourtant, c'est ce que vivent beaucoup trop souvent les adolescents quand ils atteignent un âge établi d'avance par une loi ou une politique qui fait qu'ils deviennent subitement inadmissibles aux services de santé mentale « pour enfants ». Un jour, ils y ont droit, et le lendemain, soit le jour de leur anniversaire, c'est fini. Comme l'a souligné le D<sup>r</sup> Ashok Malla, directeur de la recherche à l'Hôpital Douglas :

**Quand les adolescents atteignent un âge établi d'avance par une loi ou une politique qui fait qu'ils deviennent subitement inadmissibles aux services de santé mentale « pour enfants ». Un jour, ils y ont droit, et le lendemain, soit le jour de leur anniversaire, c'est fini.**

*[L]a ségrégation entre service pour adolescents ou enfants et service pour adultes est artificielle, selon moi, et elle est contre-productive. Il convient à tout prix de protéger les ressources destinées à ce groupe d'âge car il faut traiter de façon suivie les troubles qui apparaissent à l'adolescence en sorte que l'on puisse compter sur les compétences nécessaires quand une personne a besoin d'être soignée plutôt que de lui faire passer X nombres d'années dans tel ou tel service puis de la transférer ailleurs quand elle atteint l'âge magique de 18 ans<sup>243</sup>.*

Certaines situations décrites au Comité sont absolument absurdes, comme celle-ci, présentée par la D<sup>re</sup> Linda Bayers, directrice exécutive de Self Help Connection :

*Pour ce qui est des 17 et 18 ans, on a ouvert une clinique de santé mentale tout juste à côté d'une école secondaire, mais les jeunes devaient*

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<sup>243</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*attendre d'avoir 19 ans pour en utiliser les services. Allez comprendre!  
Nous devons faire beaucoup mieux pour aider ceux qui sont dans ce  
groupe d'âge<sup>244</sup>.*

On peut s'interroger sur les motifs qui sous-tendent ce genre de décisions, mais les conséquences sont bien réelles. Phyllis Grant-Parker décrit ainsi l'expérience de son fils :

**À l'heure actuelle, on observe des chasses gardées qui font que particuliers et organismes fonctionnent chacun de leur côté, sans contact entre eux; cette habitude doit cesser.**

*On dirait que le système s'attend à ce qu'un jeune souffrant d'une maladie mentale devienne spontanément un adulte autonome. À Ottawa, où nous résidons, nous n'avons pas pu trouver de traitement approprié à son âge. L'Hôpital pour enfants de l'Est de l'Ontario — HEEO — n'offre pas de programme du genre. La liste d'attente à la clinique de soins des premiers épisodes de psychose, à Ottawa, à l'Hôpital d'Ottawa, est de six mois. Ce faisant, mon fils a été hospitalisé dans un hôpital de soins tertiaires, parmi des adultes souffrant de maladie chronique et n'offrant pas de programme de réhabilitation. Tout cela donne peu d'espoir pour un adolescent et sa famille<sup>245</sup>.*

Les enfants et les adolescents ont besoin de services de santé mentale spécialisés, mais il n'y a aucune raison pour que de tels services soient isolés du système de santé mentale général. À l'heure actuelle, on observe des chasses gardées qui font que particuliers et organismes fonctionnent chacun de leur côté, sans contact entre eux; cette habitude doit cesser.

Il incombe aux professionnels de la santé mentale de travailler en collaboration afin d'anéantir les obstacles qui existent au sein des systèmes pour adultes et enfants et entre ces systèmes. Tous les services de traitement, qu'ils soient offerts en milieu communautaire, scolaire ou hospitalier, doivent être entièrement intégrés afin que les enfants et les adolescents bénéficient d'interventions qui leur conviennent et ce, tant qu'ils en auront besoin.

Par conséquent, le Comité recommande :

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| 19 | <b>Que les gouvernements des provinces et des territoires s'efforcent d'éliminer la compartimentation sur les plans de la législation, de l'administration ou des programmes qui les empêche de veiller comme il se doit à assurer le passage de l'adolescence à l'âge adulte et qu'elles adoptent les mesures suivantes :</b> |
|----|--|

<sup>244</sup> 10 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evc-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evc-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>245</sup> 16 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/06evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

- Que l'âge limite pour les services de santé mentale destinés aux enfants et aux adolescents soit établi en fonction de considérations d'ordre clinique plutôt que d'ordre administratif, budgétaire ou autre.
- Que, dans les cas où un âge limite est fixé, un lien soit établi entre les services offerts aux enfants et aux adolescents et les services pour adultes afin d'assurer une transition harmonieuse.
- Que, dans les cas où un âge limite est fixé, il n'y ait pas de période d'interruption où une personne est inadmissible au traitement tant dans le système pour enfants et adolescents que dans le système pour adultes.

### 6.2.3.2 Services sociaux

Les limites d'âge ont abouti à certains résultats absurdes dans le contexte des services de santé mentale, mais elles entraînent dans le domaine des services sociaux des situations qui défient l'entendement. L'échange reproduit intégralement ci-dessous, entre Andy Cox, défenseur des soins de santé mentale au Centre de santé IWK (Hôpital pour enfants) à Halifax, et le président du Comité, a eu lieu lors des audiences publiques du Comité à Halifax. La discussion ne concerne pas une personne atteinte d'une maladie mentale, mais elle illustre bien le manque de services que vivent constamment ces personnes :

**M. Cox :** *D'abord, permettez-moi de vous donner un exemple. Nous avons un jeune de 18 ans dans notre unité des malades hospitalisés. Il s'y trouve depuis octobre [sept mois]. Il n'est atteint d'aucune maladie et ne souffre d'aucun problème mental. Les services communautaires ne pouvaient l'accueillir. Il s'est présenté à l'urgence de l'IWK et a été admis à l'hôpital. Nous essayons, depuis, de lui trouver un endroit où vivre. Nous avons trois ou quatre cas de ce genre sur notre liste.*

**Le président :** *Pourquoi a-t-il été admis s'il n'avait rien?*

**M. Cox :** *Les Services communautaires ne pouvaient pas l'aider. Il est aveugle.*

**Le président :** *Vous lui avez donné un lit dans un hôpital parce que le ministère des Services communautaires, pour reprendre vos mots, ne pouvait l'aider?*

**M. Cox :** *Oui, et nous essayons, depuis, de nous battre, de porter l'affaire en appel.*

**Le président :** *Il occupe un lit d'hôpital parce qu'il n'a pas d'autre endroit où aller? Il n'est pas malade?*

**M. Cox :** *Non, il ne l'est pas.*

**Le président :** *Il n'a pas commis de crime?*

M. Cox : *Non.*

Le président : *Vous comprenez pourquoi cela ressemble, pour le simple citoyen, à...*

M. Cox : *Les cas de ce genre ne sont pas rares.*

Le président : *Ce n'est pas un cas unique?*

M. Cox : *Non*<sup>246</sup>.

Le problème semble découler du libellé de certaines lois provinciales. Comme l'explique Christine Brennan, superviseure des Services pour les jeunes et les personnes âgées au Bureau de l'ombudsman de la Nouvelle-Écosse :

**Quiconque est aux prises avec une maladie mentale ne devrait pas être abandonné dans un vide législatif entre le système pour enfants et adolescents et le système pour adultes.**

*Ce qu'il faut comprendre, c'est que la Loi sur les services à l'enfant et à la famille dispose que le ministre doit offrir des services aux enfants âgés de 15 ans et moins. Dans le cas des jeunes âgés entre 16 et 18 ans, il peut leur en offrir, mais à sa discrétion. Le mot « doit » est considéré comme une obligation. Il existe des lacunes au niveau des services offerts aux jeunes âgés de 16 et 17 ans, parce que la loi dit que le ministre peut, à sa discrétion, leur en offrir.*

*En règle générale, les nombreux jeunes qui ont besoin de services de ce genre ne respectent pas les plans d'intervention qui sont établis à leur intention et deviennent des jeunes à problème. Il est plus facile de mettre fin à une entente de soins ou de ne pas fournir de services, ce qui complique les choses, car les jeunes qui ont besoin de ces services ne peuvent y avoir accès parce qu'ils ont un problème de comportement*<sup>247</sup>.

Le Comité est d'avis que les services de santé mentale et les services sociaux sont *tous les deux* essentiels pour assurer le mieux-être. Une gamme intégrée de services d'un type ou de l'autre est bénéfique pour les enfants et les adolescents, mais les effets favorables sont décuplés si les deux systèmes sont reliés.

Quiconque est aux prises avec une maladie mentale ne devrait pas être abandonné dans un vide législatif entre le système pour enfants et adolescents et le système pour adultes.

<sup>246</sup> 10 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evc-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evc-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>247</sup> 10 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evc-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evc-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Par conséquent, le Comité recommande :

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Que les gouvernements des provinces et des territoires coordonnent les services de santé mentale et les services sociaux et, à cet égard, veillent à ce que l'âge limite pour les services sociaux destinés aux enfants et aux adolescents coïncide avec celui établi pour les services de santé mentale.

### 6.3 PÉNURIE DE PROFESSIONNELS EN SANTÉ MENTALE TRAITANT LES ENFANTS ET LES ADOLESCENTS

Pour les Canadiens, les pénuries de professionnels de la santé n'ont rien de neuf. Ni le système de santé mentale, ni le sous-système qui s'occupe des enfants et des adolescents n'y ont échappé.

**Il n'est pas suffisant toutefois d'augmenter seulement le nombre de psychiatres. Il faut également aborder la question des pénuries chez les autres professionnels de la santé mentale spécialisés dans le traitement des enfants et des adolescents, notamment les psychologues, les infirmières et les travailleurs sociaux.**

À maintes reprises, le Comité s'est fait dire qu'il faut multiplier le nombre de professionnels de la santé mentale au Canada, particulièrement ceux qui se spécialisent dans le traitement des adolescents. La D<sup>re</sup> Nasreen Roberts, directrice du Service d'urgence pour adolescents et du Service aux hospitalisés à l'Hôpital Hôtel Dieu à Kingston, a donné un exemple lors de son témoignage :

*Il est important de fournir des soins très rapidement et un service de consultation d'urgence. Je viens juste d'établir une liste d'attente des 16 écoles de médecine de partout au pays. Le temps d'attente pour le triage est de deux à quatre semaines. Le temps d'attente pour voir un professionnel varie de huit semaines à 18 mois.*

*Il y a moins de 500 psychiatres pour enfants et adolescents au pays. Si vous prenez seulement 14 p. cent des enfants atteints de troubles graves dans la population générale, ça fait 800 000 enfants partout au Canada. Je vous parle uniquement des troubles graves; ça ne comprend pas les 22 p. cent que j'aurais dû utiliser. Ce sont des chiffres très importants<sup>248</sup>.*

Étant donné que les écoles de médecine ne produisent que dix pédopsychiatres par année<sup>249</sup>, le problème dont parle la D<sup>re</sup> Roberts risque de subsister encore longtemps.

<sup>248</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>249</sup> Global Business Roundtable on Addiction and Mental Health, (septembre 2005), *Special Report to the Premiers of Canada: Guidelines for Working Parents to Promote and Protect the Mental Health of Their Children*, p. 2. Voir : [www.mentalhealthroundtable.ca](http://www.mentalhealthroundtable.ca).

Il n'est pas suffisant toutefois d'augmenter seulement le nombre de psychiatres. Il faut également aborder la question des pénuries chez les autres professionnels de la santé mentale spécialisés dans le traitement des enfants et des adolescents, notamment les psychologues, les infirmières et les travailleurs sociaux. Par conséquent, le Comité recommande :

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|----|--|
| 21 | <b>Que les pouvoirs publics prennent immédiatement des mesures pour remédier aux pénuries de professionnels de la santé mentale spécialisés dans le traitement des enfants et des adolescents.</b> |
|----|--|

### 6.3.1 Mesures de transition

Le Comité convient que les temps d'attente doivent être réduits, mais il est aussi bien conscient du fait qu'il sera extrêmement long d'accroître la capacité du système, particulièrement lorsqu'il s'agit de former des professionnels de la santé mentale spécialisés dans le traitement des jeunes.

Le Comité estime par conséquent important d'examiner des mesures qui permettront de remédier à la situation à court terme. À cet égard, la télépsychiatrie, les modèles de traitement non traditionnels et les conférences de cas peuvent être utiles selon nous. Ces mesures de transition permettront de patienter pendant la période de restructuration nécessaire afin d'accroître la capacité du système de santé mentale de venir en aide aux enfants et aux adolescents.

#### 6.3.1.1 Mettre en commun les ressources existantes — La télépsychiatrie

Le Comité a entendu des témoignages sur les avantages des nouvelles technologies. L'une d'elle — en l'occurrence la télépsychiatrie — sera examinée en détail au chapitre 12. Cependant, le Comité souhaite aborder la question dans le présent chapitre en raison de son utilité toute particulière dans le traitement des enfants et des adolescents.

**La télépsychiatrie permettra de partager les ressources existantes avec les régions mal desservies seulement si celles-ci offrent déjà un service de santé mentale de base.**

Les pénuries de professionnels de la santé mentale se font habituellement sentir avec plus d'acuité dans les régions rurales et éloignées. Les personnes vivant dans des collectivités n'offrant que peu de services de santé mentale, voire aucun, sont parfois obligées de parcourir de grandes distances pour obtenir des traitements. C'est en pensant à elles que certains témoins ont suggéré au Comité le recours accru à la télépsychiatrie. Selon Michelle Forge :

*Il n'y a aucun pédopsychiatre sur notre territoire. En toute franchise, l'accès merveilleux dont nous avons joui grâce à la télépsychiatrie — je crois que nous avons bénéficié de plus de 200 consultations psychiatriques — nous a permis de faire des choses à l'échelon communautaire que nous n'aurions pas été en mesure de faire autrement. Nous avons besoin de cet*

*accès. Nous n'en avons pas nécessairement besoin tout le temps, mais nous avons besoin de l'accès, et nous avons besoin d'un milieu pédiatrique disposé à nous soutenir*<sup>250</sup>.

Le succès de cette option repose sur l'accès à une expertise externe offerte par des professionnels de la santé *locaux*, que ce soit des psychologues, des infirmières, des travailleurs sociaux ou des médecins de premier recours. La télépsychiatrie permettra de partager les ressources existantes avec les régions mal desservies seulement si celles-ci offrent déjà un service de santé mentale de base. De plus, les professionnels de la santé locaux et leurs clients doivent vouloir et pouvoir utiliser la technologie et être réceptifs aux conseils donnés par des consultants à distance.

Par conséquent, le Comité recommande :

22	<p><b>Que le recours à la télépsychiatrie augmente dans les régions rurales et éloignées afin qu'il soit plus facile pour ces collectivités de tirer parti des services offerts par le personnel spécialisé dans la santé mentale des enfants et des adolescents.</b></p> <p><b>Que la télépsychiatrie serve à des fins tant de consultation que d'éducation et de formation des professionnels de la santé qui travaillent dans les collectivités rurales et éloignées.</b></p>
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#### 6.3.1.2 *Mettre l'accent sur des modèles de traitement non traditionnels — La thérapie de groupe*

Nombre d'experts ont suggéré le recours à des modèles de traitement non traditionnels, particulièrement la thérapie de groupe, afin de réduire les listes d'attente. Selon Andy Cox :

**De toute évidence, il y a un manque criant de professionnels de la santé mentale spécialisés dans le traitement des enfants et des adolescents.**

*[C]'est qu'il faut créer des groupes supplémentaires. Nous avons des jeunes qui pâtissent sur une liste d'attente, quand nous pourrions les regrouper et commencer à parler plus rapidement de maladie mentale, et, par conséquent, déterminer vers quels services ces jeunes devraient être dirigés*<sup>251</sup>.

Le D<sup>r</sup> Richard Goldbloom, exprimant le même point de vue, a présenté un cas décrit par la British Paediatric Association où la thérapie de groupe a été appliquée à des enfants souffrant de déficience de l'attention avec hyperactivité. D'après le D<sup>r</sup> Goldbloom :

<sup>250</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>251</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*En un an, la liste des enfants qui attendent de faire l'objet d'une évaluation au titre de l'hyperactivité avec déficit de l'attention a triplé. Pour contrer ce problème, on a tenu des séances d'information à l'intention des parents dont le nom figurait dans la liste d'attente de la clinique depuis neuf mois ou plus.*

*On a réduit la liste d'attente. Bon nombre des enfants ont commencé à suivre des traitements dans le cadre de séances collectives. On a réduit la liste d'attente de 20 mois à 0 en sept mois seulement. C'est possible<sup>252</sup>.*

De toute évidence, il y a un manque criant de professionnels de la santé mentale spécialisés dans le traitement des enfants et des adolescents. Cependant, il est possible de réduire l'impact de ce manque si l'on renseigne les spécialistes sur la meilleure façon de gérer les listes d'attente, particulièrement grâce au recours aux traitements non traditionnels. Par conséquent, le Comité recommande :

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| 23 | <b>Que l'on ait recours à des thérapies de groupe normalisées et fondées sur des données probantes, quand cela convient sur le plan clinique, afin de réduire les temps d'attente pour les enfants et les adolescents qui ont besoin de services de santé mentale.</b> |
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### 6.3.1.3 Travailler en coopération — Les conférences de cas

Le présent chapitre le montre clairement : les enfants et les adolescents sont mal servis par le système de santé mentale. Par conséquent, il faut envisager toutes les options possibles pour améliorer les niveaux de service, parmi elles les conférences de cas.

**Le Comité estime que les conférences de cas pourraient accroître l'efficacité du système de santé mentale tout en réduisant les coûts.**

Barbara Whitenect, qui était lors de son témoignage directrice intérimaire des Services à l'enfance et à la jeunesse du ministère de la Santé et du Mieux-être du Nouveau-Brunswick, décrit la situation en ces termes :

*Au Nouveau-Brunswick, nous avons notamment adopté une démarche fondée sur des conférences de cas exhaustives. [...] Souvent, en raison de la forte demande en services, des listes d'attente ou des mandats, les gens ne prennent pas le temps qu'il faut.*

*Nous devons envisager de formuler un mandat à cet égard et de le relier au financement. Les gens doivent travailler ensemble, partager avec le groupe les ressources dont ils disposent pour aider les enfants, et soumettre*

<sup>252</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*leurs enjeux à la discussion. ... Nous devons connaître et comprendre leur dynamique. Nous le pourrions si nous sommes tous assis à la même table*<sup>253</sup>.

Mme Whitenect a ensuite décrit l'incidence favorable de la mise en œuvre de la *Loi sur le système de justice pénale pour les adolescents* :

*Lorsqu'un jeune commet une infraction, le juge ordonne aux partenaires communautaires d'organiser une conférence de cas avant qu'il ne détermine la peine. C'est bien dommage que le jeune doive commettre une infraction pour qu'une conférence de cas se tienne en vertu de la loi[...]*

*Les gens disent : « J'ai des listes d'attente », et patati et patata. Si un juge leur ordonne de le faire, alors ils le font. Nous avons vu des résultats positifs. Nos gens ne sont pas surchargés, car c'est seulement dans des cas très difficiles et des situations extrêmes que nous devons partager nos ressources avec le groupe.*

*Sans vouloir trop me répéter, si nous commençons à agir de façon stratégique et à dire que notre financement dépend de l'application de ces conférences de cas, nous pourrions restructurer les méthodes de travail des gens et atteindre les résultats voulus*<sup>254</sup>.

Le Comité estime que les conférences de cas pourraient accroître l'efficacité du système de santé mentale tout en en réduisant les coûts. Cette solution est un autre exemple des mesures de transition qui peuvent aider à compenser le manque de professionnels de la santé mentale spécialisés dans le traitement des enfants et des adolescents. Par conséquent, nous recommandons :

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| 24 | <p><b>Que les gouvernements des provinces et des territoires encouragent leurs institutions sanitaires, éducatives et judiciaires à collaborer étroitement afin que les enfants et les adolescents puissent avoir toujours facilement accès aux services de santé mentale.</b></p> <p><b>Que les conférences de cas soient davantage utilisées en vue d'établir les priorités et de coordonner la prestation de services de santé mentale pour les enfants et les adolescents.</b></p> |
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<sup>253</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>254</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

## 6.4 INCLURE LES ADOLESCENTS ET LES SOIGNANTS MEMBRES DE LA FAMILLE DANS LE TRAITEMENT

Les enfants et les adolescents présentent un défi particulier pour les professionnels de la santé mentale. En effet, leur corps et leur esprit ne cessent de croître et de changer. Adapter les interventions de traitement pour tenir compte de cette réalité est un processus délicat qu'il convient d'aborder avec un grand respect pour le client et ses aidants naturels. Si l'unité familiale est dysfonctionnelle, il convient de la traiter dans son ensemble et de fournir à tous les membres l'aide dont ils ont besoin.

**Le Comité juge qu'il est important d'inclure les jeunes et les membres de leur famille à toutes les étapes du processus.**

**Il ne sera pas aisé de passer à ce modèle de prestation de services. Il faudra modifier la tournure d'esprit qui, jusqu'à maintenant, a donné un système de santé mentale conçu pour répondre aux besoins des institutions et des fournisseurs plutôt que des clients.**

Le Comité juge qu'il est important d'inclure les jeunes et les membres de leur famille à toutes les étapes du processus. D'après Judy Finlay, intervenante en chef du Bureau d'assistance à l'enfance et à la famille de l'Ontario :

*Si nous commençons à percevoir les parents et les enfants comme des collaborateurs au chapitre de l'évaluation, de la planification, de la prestation et de l'évaluation des services en santé mentale, cela va forcément mener à une intervention familiale, où l'enfant et la famille sont au centre. Tant que notre système sera axé sur le fournisseur, les familles seront toujours marginalisées. Nous devons adopter un modèle axé sur la famille qui permet à l'enfant et à la famille de bien vivre au sein de leur collectivité<sup>255</sup>.*

Il ne sera pas aisé de passer à ce modèle de prestation de services. Il faudra modifier la tournure d'esprit qui, jusqu'à maintenant, a donné un système de santé mentale conçu pour répondre aux besoins des institutions et des fournisseurs plutôt que des clients. Premièrement, il faut reconnaître que les jeunes et les familles sont des partenaires à part entière, capables de définir des solutions qui répondent le mieux à leurs besoins. Le Comité appuie sans réserve cette approche et recommande par conséquent :

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**Que des thérapies familiales fondées sur des données probantes soient appliquées afin que tous les membres de la famille aient accès à l'aide dont ils ont besoin.**

<sup>255</sup> 6 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/14ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Que les professionnels œuvrant auprès des enfants et des adolescents atteints d'une maladie mentale aient accès à des possibilités de formation leur permettant de répondre adéquatement aux besoins en santé mentale de leurs jeunes clients.

Que le traitement familial de la santé mentale soit intégré au programme d'études des professionnels de la santé mentale et des médecins de premier recours.

Que les professionnels soient indemnisés pour le temps qu'ils passent avec les soignants membres de la famille, en plus du temps consacré aux jeunes atteints de maladie mentale.

Que tous les spécialistes œuvrant auprès des enfants et des adolescents suivent une formation sur les droits de l'enfance.

## 6.5 L'AUTISME

Dans son premier rapport, le Comité a expliqué que des professionnels de la santé lui avaient souligné les obstacles à la prestation de service et que des aidants naturels lui avaient parlé du fardeau émotionnel et financier qui est le lot de ceux qui s'occupent des personnes atteintes d'autisme. Ces déclarations et un examen de la documentation nous ont amenés à parler de l'autisme comme étant un « trouble mental ». Or, il s'avère que nous aurions dû consulter des personnes atteintes d'autisme avant d'adopter cette position.

Lors des audiences publiques qui ont suivi la publication de nos rapports intérimaires sur la santé mentale, la maladie mentale et la toxicomanie, le Comité a entendu d'autres témoignages sur la question. Cette fois cependant, nous avons recueilli des points de vue fort divergents sur ce qu'est l'autisme et sur la façon dont le système de santé mentale doit traiter cette question.

Mme Norah Whitney, qui a un enfant atteint d'autisme, a déclaré que :

*Sans traitement efficace, l'autisme est un trouble permanent qui mène au placement de plus de 90 p. cent des enfants non traités dans des centres d'accueil et des établissements de logement. Seulement un enfant sur 64 réussira à s'améliorer sans bénéficier de traitement<sup>256</sup>.*

Elle a par la suite ajouté que :

*[P]resque 50 p. cent des enfants autistes qui sont traités avant leur admission à l'école, idéalement, à l'âge de deux ans, s'assimilent complètement à leurs pairs, au point de ne plus pouvoir être différenciés.*

<sup>256</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*En d'autres mots, avec ce traitement, il y a un taux de rétablissement de 47 p. cent. Maintenant, je sais que de nombreuses personnes ne croient pas au rétablissement lorsqu'il est question d'autisme, mais j'ai vu ces enfants de mes yeux, et, si je ne l'avais pas su, je n'aurais jamais pu cerner une trace d'autisme dans les mouvements de leur petit corps<sup>257</sup>.*

Selon Mme Whitney, l'autisme est une maladie<sup>258</sup> qui, si elle n'est pas traitée, a de graves conséquences pour les personnes touchées et les membres de leur famille. Elle préconise le recours précoce à l'intervention comportementale intensive (ICI), disant qu'« il s'agit du seul traitement efficace pour l'autisme<sup>259</sup> ». Elle a ajouté aussi que les aidants naturels vivent des difficultés financières en raison du coût élevé de l'ICI et du fait que les régimes de santé provinciaux n'offrent qu'une aide limitée.

Les personnes atteintes d'autisme, comme Michelle Dawson, s'opposent vivement à ces arguments. Mme Dawson a riposté en ses termes :

*Les groupes de défense des personnes autistes ont décrit les personnes autistes en utilisant les termes les plus affreux et les plus horribles. Nous nous détruisons nous-mêmes, nous détruisons nos familles et l'économie, et il est fort probable que nous ruinerons sous peu le pays tout entier tant qu'on ne nous fera pas subir des traitements coûteux. Le fait même que nous continuions d'exister, tels que nous sommes, en tant que personnes autistes, est considéré comme une atteinte à la notion même du Canada.*

*Parallèlement, les défenseurs des personnes autistes soutiennent que cette catastrophe nationale imminente peut être évitée si l'on dispose de fonds illimités pour des interventions intensives qui se fondent sur l'analyse comportementale appliquée, de type Lovaas ou autre, pour les personnes autistes de tout âge. [...]*

*[L]es aptitudes et les traits de caractère des personnes autistes sont non existants ou destructifs, inutiles et mauvais. Il y a tout à gagner et rien à perdre si nos vies sont consacrées à tâcher chaque minute d'être normal, c'est-à-dire de ne pas être autistes. L'objectif de ce type d'intervention, comme l'a écrit à maintes reprises Ivar Lovaas, est de construire une personne là où elle n'existe pas<sup>260</sup>.*

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<sup>257</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>258</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>259</sup> 15 février 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/05eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>260</sup> 21 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Mme Dawson est d'avis que l'autisme n'est pas une maladie mentale<sup>261</sup>. D'après elle, « il nous faut une source d'information exacte et objective à propos de l'autisme au Canada<sup>262</sup> » et à son avis, le présent rapport n'est pas le moyen idoine pour traiter cette question.

Le Comité reconnaît que les aidants naturels ont de la difficulté à offrir les meilleurs soins possibles aux personnes atteintes d'autisme. Les problèmes émotionnels et financiers qu'ils vivent sont bien réels, et une solution s'impose. Cependant, nous ne croyons pas que le Comité soit à même de formuler des recommandations en ce moment. Il faut approfondir l'étude du sujet si nous voulons rendre justice à une question extraordinairement complexe où la question fondamentale — soit « l'autisme est-il une maladie mentale? » — suscite la controverse<sup>263</sup>.

Dans son rapport précédent intitulé *La santé des Canadiens — Le rôle du gouvernement fédéral*, le Comité a présenté les études thématiques qu'il a l'intention de réaliser. Ces études nous tiennent à cœur, comme en témoigne la présente sur la santé mentale et la toxicomanie. Nous espérons ainsi avoir l'occasion de nous pencher sur l'autisme. En attendant, nous recommandons un débat plus approfondi entre toutes les parties prenantes. Le Comité estime en particulier que les personnes atteintes d'autisme doivent être vues comme des partenaires à parts égales dans les discussions à ce sujet.

## 6.6 CONCLUSION

Le Comité s'inquiète beaucoup de la capacité du système de santé mentale de répondre aux besoins des enfants et des adolescents. La fragmentation des services, jumelée au sous-financement, à la pénurie de professionnels de la santé mentale et au manque de participation des jeunes et de leurs familles dans les traitements à long terme ont retardé l'application des interventions, lesquelles sont inadéquates de toute façon. La situation est, pour tout dire, inacceptable. Il faut investir beaucoup plus dans la santé mentale des enfants si nous voulons corriger son statut de parent pauvre au sein d'un système de santé mal en point. Nous estimons qu'un investissement dans l'intervention précoce, effectuée selon nos recommandations et visant à restructurer le système de toute urgence, entraînera d'importantes économies à long terme pour le système de soins de santé et bien plus.

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<sup>261</sup> 21 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>262</sup> 21 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/23eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>263</sup> Tant le *Manuel diagnostique et statistique des troubles mentaux* (DSM), publié par l'American Psychiatric Association, que la *Classification internationale des maladies*, publiée par l'Organisation mondiale de la Santé, classent l'autisme parmi les troubles mentaux. Cependant, certains spécialistes offrent un autre point de vue. Voir, par exemple, le témoignage du professeur Greg O'Brien devant le Parlement du Royaume-Uni, en ligne à <http://www.publications.parliament.uk/pa/jt200405/jtselect/jtment/79/4102708.htm>, et celui des D<sup>rs</sup> Betty Jo Freeman et Ritvo (12 Employee Benefits Cases 1221, 19 A.L.R. 5<sup>th</sup> 1017, 910, F.2d 534 (9<sup>th</sup> Cir.)), en ligne à <http://www.geocities.com/fishstep/Kunin.html>.



### 7.1 INTRODUCTION

*Lorsqu'on parle de maladie mentale chronique grave, on ne parle pas de la maladie d'Alzheimer ni de la démence, comme tout le monde pourrait tout de suite penser. On parle des adultes âgés et des personnes âgées qui ont souffert toute leur vie de schizophrénie, d'un trouble bipolaire ou d'un trouble de la personnalité. Comme les gens vieillissent, c'est certain que nous allons voir plus souvent ce genre de cas. Ces personnes sont probablement les plus difficiles, les plus vulnérables et les plus oubliées que nous servons. — Suzanne Crawford<sup>264</sup>*

Aujourd'hui, les Canadiens ont une espérance de vie proche de 80 ans<sup>265</sup>. Par suite de ce fait et de la baisse du taux de natalité, les personnes âgées de 65 ans et plus représentent une proportion importante et croissante de notre population<sup>266</sup>. Et parmi ces personnes âgées, 20 p. 100 sont atteintes de maladies mentales<sup>267</sup>.

**Il manque de programmes de traitement spécialisés et de services de soutien pour les aînés, et il n'y a pas assez de recherche et d'échange de renseignements pour que ces programmes et services puissent être développés et améliorés.**

Même si ce taux d'incidence est comparable à celui d'autres groupes d'âge, il masque des problèmes alarmants, comme le fait que 80 à 90 p. 100 des pensionnaires des établissements de soins de longue durée ont une maladie mentale<sup>268</sup> ou une forme de déficience intellectuelle<sup>269</sup>. De plus, ce chiffre ne dit

**Les efforts déployés pour remédier aux lacunes des services existants de traitement et de soutien sont régulièrement entravés par l'application d'une philosophie consistant à « caser » ou à « parquer » ceux qui ont le malheur d'être à la fois âgés et atteints de troubles mentaux.**

<sup>264</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>265</sup> Statistique Canada, *Le Quotidien*, Statistiques démographiques, le 28 septembre 2005, <http://www.statcan.ca/Daily/Francais/050928/q050928a.htm>.

<sup>266</sup> On estime que, d'ici 2016, les aînés représenteront plus de 16 p. 100 de la population, par rapport à 13 p. 100 aujourd'hui. Penny MacCourt, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 4. D'ici 2026, on estime qu'un Canadien sur cinq sera âgé de 65 ans ou plus, par rapport à un sur huit en 2001. Statistique Canada, 2002, *Vieillir au Canada : Rapport préparé par Santé Canada de concert avec le Comité interministériel sur les questions relatives au vieillissement et aux aînés*, p. 1.

<sup>267</sup> *Ibid.*

<sup>268</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, novembre 2004, Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 5, section 5.1.3, p. 97.

<sup>269</sup> E. Drance, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 2.

pas qu'un nombre croissant d'âinés ont des problèmes particulièrement aigus comprenant des taux élevés de maladie d'Alzheimer et des types de démence qui y sont associés et, dans le cas des hommes, un taux de suicide très important<sup>270</sup>.

Au cours de ses consultations, le Comité a noté un certain nombre de problèmes importants qui, même s'ils sont caractéristiques des âinés, sont liés aux grandes lacunes du système de santé mentale. Malheureusement, le Comité a constaté que, dans le cas des âinés, comme dans celui des autres groupes de la population, les services disponibles de traitement et de soutien sont en général insuffisants. Plus particulièrement, il manque de programmes de traitement spécialisés et de services de soutien pour les âinés, et il n'y a pas assez de recherche et d'échange de renseignements pour que ces programmes et services puissent être développés et améliorés.

De plus, il arrive souvent que les âinés n'aient pas accès aux services de santé mentale là où ils vivent. C'est une considération importante, compte tenu de leur mobilité limitée. Le fait que les âinés font souvent la transition entre des soins communautaires et des soins donnés en établissement n'est pas toujours pris en considération et prévu dans la planification, ce qui complique la transition pour la personne en cause et la rend inefficace. Enfin, les efforts déployés pour remédier aux lacunes des services existants de traitement et de soutien sont régulièrement entravés par l'application d'une philosophie consistant à « caser » ou à « parquer » ceux qui ont le malheur d'être à la fois âgés et atteints de troubles mentaux. Il est triste de constater qu'on s'occupe fort peu du rétablissement des âinés atteints d'une maladie mentale.

## 7.2 BESOINS DE TRAITEMENTS SPÉCIALISÉS

Les âinés ne sont pas tout simplement des adultes âgés dont les problèmes mentaux peuvent être traités dans le cadre de programmes génériques censés convenir à tous les âges. Ils forment un segment démographique aux caractéristiques très particulières, dont les besoins de santé mentale se distinguent de ceux d'autres groupes. Un participant à la consultation en ligne du Comité a dit ceci à cet égard :

**... les âinés sont un groupe distinct. Ils méritent qu'on élabore des stratégies, des programmes et des politiques adaptés aux enjeux qui les intéressent[...]**

**— Jennifer Barr**

*Les âinés ayant des troubles mentaux chroniques sont très loin de recevoir les mêmes services que les autres membres de la population. Ils ne sont souvent pas « adaptés » aux services et programmes de santé mentale en établissement conçus pour les adultes (parce qu'ils peuvent avoir des déficiences physiques, fonctionnelles et intellectuelles liées au vieillissement, en sus de leurs troubles mentaux chroniques). Ils ne sont pas nécessairement « adaptés » non plus aux programmes à long terme*

<sup>270</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, novembre 2004, Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 5, section 5.1.3, p. 97.

*(car ils peuvent être physiquement et fonctionnellement bien portants).*  
—Anonyme

M<sup>me</sup> Jennifer Barr, du Centre de toxicomanie et de santé mentale, partage ce point de vue. Pour elle :

*... les aînés sont un groupe distinct. Ils méritent qu'on élabore des stratégies, des programmes et des politiques adaptés aux enjeux qui les intéressent, tout comme d'autres groupes ont besoin de programmes adaptés, à toutes les étapes de la vie. On ne peut pas servir tout le monde de la même façon<sup>271</sup>.*

Il est en outre important de reconnaître que les aînés ne forment pas un groupe homogène. Ils peuvent avoir des âges très différents, chaque groupe d'âge ayant des besoins particuliers en matière de santé mentale.

La prévalence de la maladie d'Alzheimer illustre bien ce point. Il est notoire que cette maladie touche les aînés d'une façon disproportionnée. Toutefois, si elle atteint une personne sur 13 au-dessus de 65 ans, son taux de prévalence grimpe à une personne sur trois au-dessus de 85 ans<sup>272</sup>.

Il est important de tenir compte de cette diversité dans la prestation des services de santé mentale et dans la recherche sur laquelle ces services sont censés se baser. Comme l'a souligné Faith Malach, directrice administrative de la Coalition canadienne pour la santé mentale des personnes âgées, dans son témoignage devant le Comité :

*... lorsqu'on parle des « personnes âgées », je ne sais pas vraiment si on présume qu'on parle d'un large éventail de personnes... Il existe d'énormes différences entre les personnes âgées de 65 ans et celles qui ont 95 ans, et lorsqu'on recueille des indicateurs et qu'on examine les statistiques, on ne doit pas oublier, que même chez les personnes âgées, la fourchette d'âge peut être énorme<sup>273</sup>.*

Cette incompréhension par le système de santé mentale de la diversité et des particularités des besoins des aînés pourrait être attribuable, du moins en partie, à l'insuffisance des échanges d'information entre les chercheurs en gérontologie, de même qu'entre les professionnels qui soignent les personnes âgées et l'ensemble de la communauté des soignants en santé mentale et en toxicomanie. Les témoins sont allés jusqu'à soutenir que les chercheurs canadiens travaillant dans le domaine de la santé mentale des aînés « ne savent

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<sup>271</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>272</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, novembre 2004, Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 5, section 5.1.3, p. 97.

<sup>273</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

pas du tout qui d'autre le fait<sup>274</sup> », malgré leur nombre assez réduit. D'après Jennifer Barr, la solution serait la suivante :

*Nous devons diffuser l'information sur la gérontologie aux fournisseurs de services liés aux maladies mentales et à la toxicomanie. Nous devons diffuser l'information sur les maladies mentales et la toxicomanie aux fournisseurs de services gérontologiques. Évidemment, je présente cela de façon un peu simpliste. Bien sûr, toute cette documentation doit être adaptée au public visé. Encore une fois, elle doit être destinée aux personnes concernées et au rôle particulier qu'elles jouent. Pour ce qui est de la mise en commun des connaissances, elle doit être accompagnée de campagnes étendues de sensibilisation du public, d'entraide et de soutien aux bénéficiaires<sup>275</sup>.*

Compte tenu de ce qui précède, le Comité recommande :

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|----|---|
| 26 | <p>Que l'un des objectifs du Centre d'échange des connaissances devant être créé à la Commission canadienne de la santé mentale (voir le Chapitre 16) soit de favoriser l'échange d'information parmi les chercheurs en gérontologie eux-mêmes, de même qu'entre les fournisseurs de services spécialisés aux personnes âgées et les autres fournisseurs de services en santé mentale et en toxicomanie.</p> <p>Que la Commission canadienne de la santé mentale encourage la recherche sur les vastes éventails d'âges, d'environnements (par exemple, les services communautaires par opposition aux soins en établissement), de comorbidités et de questions culturelles ayant des incidences sur la santé mentale des aînés, et favorise l'adoption de pratiques exemplaires dans les programmes de santé mentale destinés aux aînés, de façon à combattre la marginalisation des adultes âgés inscrits à des programmes de traitement censément adaptés à tous les âges.</p> |
|----|---|

## 7.3 LIEU DE PRESTATION DES SERVICES

### 7.3.1 La réalité : un modèle de soins axé sur le fournisseur

Le système de santé mentale est axé sur les fournisseurs puisqu'il est généralement structuré de façon à répondre principalement aux besoins des fournisseurs de services individuels et institutionnels, et non de leurs clients. Par exemple, de nombreux services de santé mentale ne sont offerts que dans les hôpitaux ou d'autres établissements où des fournisseurs de soins

<sup>274</sup> Faith Malach, 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>275</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

ont leur siège. M<sup>me</sup> Charmaine Spencer, professeur auxiliaire de gérontologie à l'Université Simon Fraser, a décrit d'autres caractéristiques de ce modèle axé sur le fournisseur :

*... elles [les personnes âgées] sont limitées à des choses comme une consultation de dix minutes ou... [l'application du] principe « une consultation, un problème de santé ». Elles voient des signes qui leur font croire ça. Cela n'est pas propice à l'établissement d'un bon service en santé mentale, à quelque niveau que ce soit, ni à quelque service de santé pour les adultes âgés. En ce qui concerne les adultes âgés se trouvant dans cette situation, lorsqu'on s'occupe d'un problème à la fois, on en vient à adopter une méthode de gestion de crise...<sup>276</sup>*

Pour les aînés, les difficultés occasionnées par le modèle de soins axé sur le fournisseur varient selon leur rôle comme aidants naturels pour un autre membre de la famille, leurs moyens financiers et la mesure dans laquelle leur mobilité est restreinte.

La mobilité peut être limitée par différents facteurs. Certains aînés pourraient avoir de la difficulté à conduire ou être incapables de le faire. Dans beaucoup de collectivités, les transports en commun peuvent être mal conçus ou ne pas exister du tout, surtout en dehors des centres urbains. Les aînés peuvent même trouver difficile de marcher si les trottoirs sont mal entretenus, particulièrement en hiver. D'ailleurs, même en l'absence de difficultés de transport, les aînés peuvent devoir s'occuper d'un conjoint ou d'un partenaire, ce qui peut les empêcher de sortir de chez eux, surtout s'ils n'ont pas les moyens d'obtenir des services de relève ou de prendre un taxi. Bref, le modèle de soins axé sur le fournisseur comporte d'importants obstacles structurels qui empêchent les aînés de recourir aux services offerts.

### 7.3.2 L'idéal: un système de santé mentale axé sur le client

La solution apparemment évidente consiste à offrir des services de santé mentale là où vivent les adultes âgés, que ce soit chez eux, au domicile de ceux qui les soignent ou dans un établissement de soins actifs ou de soins de longue durée. Voici ce qu'en a dit Jennifer Barr :

**La solution apparemment évidente consiste à offrir des services de santé mentale là où vivent les adultes âgés, que ce soit chez eux, au domicile de ceux qui les soignent ou dans un établissement de soins actifs ou de soins de longue durée.**

*... cela m'amène [à] quelque chose qui s'assimile à [la] recommandation [du Comité] relative à des programmes en milieu scolaire pour les jeunes, où vous voulez offrir des programmes qui sont facilement accessibles, par exemple, le fait d'affecter un conseiller en toxicomanie ou d'établir un groupe de soutien en santé mentale dans le milieu scolaire. Parallèlement, puisque les personnes âgées sont, pour un certain nombre de raisons, moins susceptibles de se rendre dans un établissement où le traitement est offert, nous devons dispenser les services relatifs à la toxicomanie et à la*

<sup>276</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*santé mentale là où se trouvent les personnes âgées, dans une diversité de contextes*<sup>277</sup>.

Il ne suffit cependant pas d'offrir des services de santé mentale là où vivent les aînés. Il faut aussi mettre à leur disposition une pleine gamme de services adaptés à leurs besoins. Comme l'a noté Penny MacCourt dans le mémoire qu'elle a présenté au Comité au nom de la British Columbia Psychogeriatric Association :

*Pour beaucoup d'aînés, les facteurs qui influent sur la santé mentale sont souvent liés à... des lacunes dans leur système ou leur environnement de soutien social. Les politiques et les services actuels... s'inscrivent ordinairement dans un modèle biopsychosocial... axé sur la composante biomédicale. Le modèle biomédical... est centré sur la pathologie individuelle, entraînant l'organisation de services et de programmes visant principalement à diagnostiquer et à traiter la maladie mentale. Les efforts sont étroitement centrés sur le traitement et les soins aigus. Le paradigme biomédical a amené les responsables des soins à négliger... les interventions non médicales et les services communautaires plus étendus qui sont nécessaires au soutien de la santé mentale des aînés*<sup>278</sup>.

De ce fait, les services doivent être rapprochés de leurs clients et être développés de façon à s'adapter aux besoins de chaque population locale particulière. Une fois cela fait, une dernière étape reste encore à franchir. Il faut en effet éliminer l'écart qui existe entre les différents endroits où vivent les aînés. Autrement dit, il est nécessaire de tenir compte du fait qu'avec le temps, les aînés passent souvent d'un endroit à un autre.

### **7.3.2.1 Adaptation des services aux endroits où vivent les aînés**

La vie des aînés consiste souvent en une série de transitions. Si certaines personnes âgées vivent confortablement chez elles jusqu'à leur décès, beaucoup d'autres passent successivement de leur propre domicile à celui d'aidants naturels membres de la famille, puis à des établissements de soins actifs et de soins de longue durée. La succession exacte de ces transitions est difficile à prédire, même si nous savons que beaucoup d'aînés sont déplacés ainsi d'une façon ou d'une autre pendant une période qui s'étend souvent sur trois ou quatre décennies.

#### **7.3.2.1.1 Aînés vivant chez eux**

Le Comité croit que les aînés qui ont des troubles mentaux devraient, comme ceux qui sont atteints de maladies physiques, pouvoir recevoir des soins et des services de soutien chez eux. Cela devrait comprendre des services de traitement à domicile dispensés par un fournisseur compétent de soins de santé mentale ainsi que des services gratuits ou peu coûteux de livraison de médicaments.

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<sup>277</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>278</sup> P. MacCourt, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 6.

Toutefois, comme nous l'avons mentionné ci-dessus, la prestation de services médicaux ou psychothérapeutiques ne suffit pas. Les aînés ont d'autres besoins, aussi bien physiques (par exemple, aide pour les activités courantes d'entretien du domicile, les achats, la cuisine, le nettoyage et le bain) que sociaux (par exemple, visiteurs ou accès à des services de bibliothèque).

Même si on a reconnu dans une certaine mesure les avantages qu'il y a pour les aînés à rester chez eux, les possibilités qui existent actuellement sont limitées. Comme l'a dit Terry McCullum, chef de la direction de l'organisation Leap of Faith, Toronto (LOFT) Community Services :

**Le Comité croit que les aînés qui ont des troubles mentaux devraient, comme ceux qui sont atteints de maladies physiques, pouvoir recevoir des soins et des services de soutien chez eux.**

*Il n'existe pratiquement aucune ressource de soutien à domicile pour les adultes âgés ayant une maladie mentale ou une toxicomanie... Les seules possibilités, pour eux, sont l'hôpital ou un établissement de soins de longue durée, mais ces options sont coûteuses, les privent de leur liberté et ne sont souvent pas nécessaires<sup>279</sup>.*

La quasi-absence de ressources de soutien à domicile n'est pas seulement attribuable à des contraintes financières. Comme l'a dit le D<sup>r</sup> Martha Donnelly, chef du département de gériatrie communautaire à l'Hôpital général de Vancouver :

*... la plupart des aînés aimeraient mieux rester chez eux, et c'est une bonne chose tant qu'on peut y obtenir les services requis. Le problème, c'est que certaines politiques ne permettent pas de fournir à domicile les services de soutien nécessaires aux clients souffrant de troubles mentaux. Par exemple, en Colombie-Britannique, on offre actuellement des services d'aide ménagère aux personnes qui ont besoin d'aide pour prendre leur bain. Toutefois, lorsque les gens sont méfiants et s'isolent, nous ne pouvons pas leur fournir ce genre de service. On attache de l'importance à leur santé physique, mais pas autant à leur santé mentale<sup>280</sup>.*

Il ne devrait pas en être ainsi. Le Comité appuie fortement le principe que les personnes atteintes aussi bien de maladies mentales que de maladies physiques devraient disposer d'une pleine gamme de services de traitement et de soutien. Nous appuyons également la création de logements abordables (c'est-à-dire subventionnés) et supervisés (c'est-à-dire avec services de soutien sur place pour les activités de la vie quotidienne). Par conséquent, le Comité recommande :

<sup>279</sup> R. Fine, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, annexe 1, p. 1.

<sup>280</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Que des montants prélevés sur le Fonds de transition de la santé mentale (voir le Chapitre 16) soient mis à la disposition des provinces et des territoires afin de financer des initiatives conçues pour faciliter la vie dans la collectivité des aînés atteints de maladie mentale, ces initiatives pouvant comprendre notamment :

- des visites à domicile de fournisseurs de soins en santé mentale adéquatement rémunérées;
- une pleine gamme de services pratiques et de services de soutien social à domicile pour les aînés ayant une maladie mentale;
- un niveau de soutien des aînés ayant une maladie mentale qui soit au moins équivalent au niveau de soutien offert aux aînés ayant une maladie physique, où qu'ils vivent;
- un plus grand nombre de logements abordables et supervisés pour les aînés ayant une maladie mentale.

#### 7.3.2.1.2 Aînés vivant chez des aidants familiaux

Nous avons examiné au chapitre 5 la question du soutien aux aidants familiaux. Le Comité croit néanmoins qu'il est nécessaire de revenir ici sur les pressions particulières qui s'exercent sur ceux qui donnent des soins à des aînés ayant une maladie mentale.

**Les responsabilités d'aidant qu'assument des aînés les exposent eux-mêmes à des troubles mentaux**

Tout d'abord, les aînés ayant une maladie mentale sont souvent soignés par un conjoint ou un partenaire également âgé. Ces aidants peuvent eux-mêmes avoir des problèmes physiques ou mentaux qui se répercutent sur leur relation avec leur proche et qui accentuent le besoin de services de santé mentale et de soutien des deux parties. Comme l'a signalé Penny MacCourt dans son mémoire au Comité, les responsabilités d'aidant qu'assument des aînés les exposent eux-mêmes à des troubles mentaux :

**On ne devrait pas s'attendre à ce que les aidants familiaux se substituent aux services et soutiens qui devraient être offerts à des proches malades vivant seuls.**

*Les femmes qui donnent des soins, surtout à des personnes atteintes de démence... courent elles-mêmes un risque accru de dépression. Les aidants qui ne peuvent pas compter sur un soutien social appréciable, qui se*

*sentent surchargés ou souffrent de solitude sont plus susceptibles de tomber dans la dépression que des aidants ayant un bon soutien social*<sup>281</sup>.

Ensuite, les aînés ayant une maladie mentale sont souvent atteints en même temps de nombreuses autres déficiences physiques et mentales. Par conséquent, ils peuvent exiger de leurs aidants plus de soins qu'un proche plus jeune. Karen Henderson a bien décrit cette réalité dans son article intitulé « Faire face à la dichotomie : enjeux de santé mentale des soignants naturels » :

Mon expérience en tant que soignante m'a appris qu'en raison des nombreuses déficiences physiques et cognitives dont souffrait mon père, j'ai dû ajouter les rôles de conjointe, parent, aide-soignante, amie, chauffeur, preneuse de décisions, intervenante, directrice de personnel, directrice financière et planificateur funéraire à mon rôle de fille. Comment parvient-on à remplir tous ces rôles et à en sortir indemne<sup>282</sup>?

Même si elle n'était pas elle-même âgée, M<sup>me</sup> Henderson a fini par sombrer dans la dépression parce qu'elle a assumé la responsabilité de soigner son père atteint de troubles mentaux.

En plus de reconnaître la valeur des aidants familiaux et de les aider dans ce rôle, il faudrait prendre des mesures pour minimiser le risque qu'ils ne soient eux-mêmes atteints de troubles mentaux. En particulier, on ne devrait pas s'attendre à ce que les aidants familiaux se substituent aux services et soutiens qui devraient être offerts à des proches malades vivant seuls. Par conséquent, le Comité recommande :

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**Que les aînés atteints de maladie mentale vivant chez des aidants familiaux soient admissibles à tous les services de santé et de soutien qui leur seraient offerts s'ils vivaient seuls.**

#### **7.3.2.1.3 Aînés vivant dans des établissements de soins actifs ou de soins de longue durée**

Dans le modèle de soins axé sur le fournisseur, on pourrait s'attendre à ce que les aînés bénéficient de services adéquats de santé mentale dans les hôpitaux de soins actifs où sont basés la plupart des fournisseurs de services. Toutefois, il arrive trop souvent que ce ne soit pas le cas. Cette situation est notamment attribuable à la

**Beaucoup d'adultes âgés sont « logés » à tort dans des établissements de soins actifs. La solution consiste à faciliter l'accès à d'autres établissements.**

<sup>281</sup> P. MacCourt, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 4.

<sup>282</sup> K. Henderson, octobre 2002, « Faire face à la dichotomie : enjeux de santé mentale des soignants naturels », dans *Écrits en Gérontologie : Santé mentale et vieillissement*, Conseil consultatif national sur le troisième âge, n° 18, [http://www.naca-ccnta.ca/writings\\_gerontology/writ18/writ18\\_4\\_f.htm](http://www.naca-ccnta.ca/writings_gerontology/writ18/writ18_4_f.htm).

perception généralisée, dans les établissements de soins actifs, que les adultes âgés ayant une maladie mentale devraient être soignés dans des centres de soins de longue durée, de façon à « conserver » les ressources limitées des hôpitaux pour des malades plus prioritaires.

Le D<sup>r</sup> Elizabeth Drance, qui est gériatropsychiatre, a parlé de cette perception et de ses effets sur les aînés dans le mémoire qu'elle a présenté au Comité :

*... nos frères aînés sont encore considérés comme des « usurpateurs de lits » et des « problèmes de placement » dans les établissements de soins actifs, qui s'efforcent par tous les moyens de libérer des lits. Les fournisseurs de notre système de soins actifs ne comprennent pas vraiment l'importance de l'admission à des fins non urgentes d'évaluation gériatrique médicale et psychiatrique, qui éviterait d'encombrer les salles d'urgence.*

*Beaucoup croient que nos frères aînés n'ont jamais besoin d'être admis à l'hôpital et que les lits qu'ils occupent devraient uniquement servir à réduire l'encombrement des salles d'urgence. Les contraintes imposées au système des soins actifs nous incitent à renoncer de plus en plus à l'idée de créer un environnement de soins actifs conçu pour les personnes âgées, ce qui intensifie pour eux le stress de l'hospitalisation et nuit à leur santé mentale<sup>283</sup>.*

Le Comité croit que tous les Canadiens, où qu'ils soient, devraient avoir accès en tout temps au système de soins actifs. Les aînés ayant une maladie mentale ont parfois besoin d'être hospitalisés. Ils devraient avoir facilement accès à ce service. Nous reconnaissons cependant que beaucoup d'adultes âgés sont « logés » à tort dans des établissements de soins actifs. La solution consiste à faciliter l'accès à d'autres établissements.

Lorsque les aînés ne peuvent plus rester ni chez eux ni chez des aidants familiaux, les établissements de soins de longue durée constituent souvent l'étape suivante. Comme l'a dit cependant le D<sup>r</sup> Drance, les besoins des pensionnaires de ce qu'elle appelle les « foyers de soins » ont considérablement évolué ces derniers temps :

*... J'ai vu la population d'aînés des environnements de soins complexes [foyers de soins]... évoluer considérablement dans les 15 dernières années. À mesure qu'un plus grand nombre d'aînés restent chez eux ou vivent dans des milieux « supervisés », les gens dont nous nous occupons dans nos foyers de soins viennent chez nous pour les raisons... suivantes :*

- *Déficiences intellectuelles et démence ...*
- *Maladies physiques graves et complexes qui réduisent la mobilité*

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<sup>283</sup> E. Drance, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 1.

- Soins de fin de vie
- Diverses combinaisons de ce qui précède<sup>284</sup>.

Le point de vue du D<sup>r</sup> Drance est partagé par Annette Osted, directrice exécutive du Collège des infirmières et infirmiers psychiatriques autorisés du Manitoba, qui a dit au Comité :

*On doit s'adapter aux changements de populations dans les foyers de soins personnels en modifiant les services offerts et la façon dont on les dispense. Il y a 30 ans, les résidents des foyers de soins personnels étaient des personnes frêles et des personnes âgées. Aujourd'hui, de 75 à 85 p. 100 de la population des foyers de soins personnels sont des personnes qui souffrent de troubles cognitifs ou de troubles de santé mentale<sup>285</sup>.*

Les conséquences de cette évolution n'ont pas fait l'objet d'une attention suffisante : les effectifs n'ont pas été augmentés en conséquence<sup>286</sup>, le perfectionnement des soignants n'a pas bénéficié d'un soutien suffisant<sup>287</sup> et on n'a pas suffisamment amélioré les services de santé mentale et de soutien sur place pour répondre aux besoins de soins plus intenses et de traitements différents que cette évolution a entraînés. Les effets de cette situation peuvent comprendre l'administration de quantités excessives de médicaments<sup>288</sup>, le recours à l'immobilisation chimique<sup>289</sup> et la prestation de services ne répondant qu'aux besoins les plus élémentaires ou à de simples exigences de garde<sup>290</sup>, le but étant de « parquer » les aînés les plus vulnérables de notre société.

**Aujourd'hui, de 75 à 85 p. 100 de la population des foyers de soins personnels sont des personnes qui souffrent de troubles cognitifs ou de troubles de santé mentale.**

— Annette Osted

**Les conséquences de cette évolution n'ont pas fait l'objet d'une attention suffisante**

Il existe d'autres possibilités. Des services de santé mentale peuvent être transférés des établissements de soins actifs aux établissements de soins de longue durée. Les services de soutien peuvent être adaptés pour refléter la transition entre la fragilité physique et la fragilité mentale. Les membres du Comité dont un membre de la famille vit dans un établissement de soins de longue durée ont parlé de leur propre expérience des jardins intérieurs protégés, grâce auxquels il n'est plus nécessaire d'immobiliser les aînés atteints de démence.

<sup>284</sup> *Ibid.*, p. 2.

<sup>285</sup> 31 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>286</sup> 31 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>287</sup> E. Drance, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 2-3.

<sup>288</sup> M. MacIssac, 10 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evd-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evd-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>289</sup> A. Osted, 31 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/16eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>290</sup> E. Drance, juin 2005, mémoire présenté au Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, p. 3.

Aménagées dans les établissements de soins de longue durée, de telles zones permettent de laisser les pensionnaires errants se promener librement en toute sécurité.

Menna MacIssac, directrice des Programmes et des opérations à la Société Alzheimer de la Nouvelle-Écosse, a confirmé la mise en place de pratiques exemplaires pour la construction des établissements de soins de longue durée, pratiques qui constituent pour elle un moyen de « changer l'environnement physique et pharmacologique dans lequel les personnes atteintes de démence vivent actuellement<sup>291</sup> ».

Le Comité recommande donc :«

29 Que des efforts soient déployés, lorsqu'il est médicalement possible de le faire, pour transférer les aînés atteints de maladie mentale gardés dans des établissements de soins actifs vers des établissements de soins de longue durée ou des logements appropriés en facilitant l'accès à des solutions autres que l'hospitalisation.

Que les compétences requises des membres du personnel des établissements de soins de longue durée soient révisées et adaptées, grâce à la mise en œuvre des programmes de formation nécessaires, pour s'assurer que le transfert de responsabilité, à l'égard des personnes atteintes de maladie mentale, des établissements de soins actifs aux établissements de soins de longue durée permet de mettre à la disposition des pensionnaires, sur place, des services de santé mentale suffisants sur le plan clinique.

### 7.3.2.2 Gestion de la transition

Même s'il est impossible de prédire quand des gens devront partir de chez eux pour aller chez un proche, à l'hôpital ou dans un établissement de soins de longue durée, il est malheureusement possible d'affirmer que la transition ne sera pas facile. Souvent, elle sera inefficace et malcommode; au pire, elle pourrait être dangereuse. Pour le D<sup>r</sup> Drance, la situation actuelle est la suivante :

**Même s'il est impossible de prédire quand des gens devront partir de chez eux pour aller chez un proche, à l'hôpital ou dans un établissement de soins de longue durée, il est malheureusement possible d'affirmer que la transition ne sera pas facile.**

*Beaucoup de services sont offerts, mais actuellement, lorsqu'une personne âgée en perte d'autonomie ou un être cher se demande qui appeler, où appeler, ce rôle de navigateur est essentiel. Les médecins de famille doivent eux aussi pouvoir naviguer dans le système. Nous n'avons pas*

<sup>291</sup> 10 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evd-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/15evd-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

*réussi à regrouper tous ces services et à aider les gens à y accéder relativement facilement. C'est un système incroyablement complexe*<sup>292</sup>.

On peut envisager différentes solutions à ce problème. Premièrement, des ressources peuvent être mises à contribution pour aider les aînés et les aidants familiaux à mieux naviguer dans le système actuel, en recourant par exemple à des « navigateurs » professionnels. Deuxièmement, il serait possible de mieux centraliser les services de transition à des endroits traditionnels, c'est-à-dire là où les fournisseurs de services se trouvent actuellement (en attendant la mise en œuvre des réformes recommandées ci-dessus). Troisièmement, les services peuvent être transférés à des endroits centraux, comme les établissements de soins de longue durée où vivent de nombreux aînés.

Le Comité croit que la dernière option est la plus avantageuse. Toutefois, nous proposons d'aller encore plus loin. En sus de centraliser les services aux endroits où vivent beaucoup d'aînés, nous croyons que différents « foyers » pour personnes âgées devraient être établis très près les uns des autres, peut-être sous un même toit. Menna MacIssac a évoqué une solution de ce genre :

*Actuellement, il existe des établissements, dont un ici à Capital [Capital Health, Halifax (Nouvelle-Écosse)] qui s'appelle Northwood, qui offrent toute une gamme de services et différents modes d'hébergement. Comme les besoins changent avec le temps — et je ne parle pas nécessairement des patients atteints de démence, mais aussi des personnes qui nécessitent des soins —, les gens peuvent se prévaloir des différentes options qui s'offrent à eux. C'est donc une possibilité qu'il faudrait aussi examiner*<sup>293</sup>.

Ce modèle a l'avantage de s'attaquer simultanément aux problèmes liés à la mobilité et à la transition entre des environnements différents. Il permet également de tenir compte des situations dans lesquelles des couples âgés ayant besoin de soins différents peuvent vivre dans les milieux les mieux adaptés à leurs besoins sans que les membres du couple soient obligés de s'éloigner l'un de l'autre.

Le Comité recommande donc :

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<sup>292</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>293</sup> 10 May 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/15evd-e.htm?Language=E&Parl=38&Ses=1&comm_id=47).

Que différents services dispensés en établissement destinés aux personnes âgées atteintes de maladie mentale soient intégrés ou établis tout près les uns des autres (par exemple, logements supervisés et établissements de soins de longue durée) pour que la transition de l'un à l'autre puisse se faire d'une façon efficace et sûre.

Que tous les efforts possibles soient faits pour permettre aux couples âgés de continuer à vivre ensemble ou tout près, indépendamment du niveau de service et de soutien dont chaque membre du couple a besoin.

#### 7.4 LE DOUBLE PRÉJUDICE DE LA MALADIE MENTALE ET DU VIEILLISSEMENT

D'après les témoignages présentés au Comité, les services de santé mentale et de soutien offerts aux aînés ne sont pas à la mesure de leurs besoins réels. Pourquoi en est-il ainsi? Ayant examiné toutes les données recueillies, nous avons abouti à la conclusion que Robena Sirett, gestionnaire des services de santé mentale aux adultes âgés de la Vancouver Coastal Health Association, avait raison de dire ce qui suit :

**... j'aimerais qu'on envisage l'adoption de stratégies pour éliminer la double stigmatisation de la maladie mentale et du vieillissement. Ce sont deux sources de stigmatisation très puissantes, et, ensemble, elles peuvent influencer sur les soins que les gens demandent et reçoivent.**  
— Robena Sirett

*Un deuxième aspect... que j'aimerais qu'on envisage est l'adoption de stratégies pour éliminer la double stigmatisation de la maladie mentale et du vieillissement. Ce sont deux sources de stigmatisation très puissantes, et, ensemble, elles peuvent influencer sur les soins que les gens demandent et reçoivent<sup>294</sup>.*

La stigmatisation peut être subtile, se manifestant par exemple dans la tendance qu'on a à considérer les jeunes adultes comme la norme pour tous les groupes d'âge<sup>295</sup>, ce qui justifie d'exclure les aînés des lignes directrices sur la santé mentale<sup>296</sup> et de faire abstraction de leur besoin de programmes de traitement spécialisés. La stigmatisation peut également revêtir des formes plus ouvertes, comme dans la tendance à établir les services de santé mentale et de soutien à des endroits inaccessibles pour ceux qui ont des déficiences physiques ou mentales.

<sup>294</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>295</sup> C. Spencer, 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>296</sup> P. MacCourt, 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

La stigmatisation s'exprime aussi dans le fatalisme qui caractérise trop souvent l'attitude de la société envers les aînés. On fait souvent abstraction de leurs symptômes de détresse en disant qu'« ils se font vieux » ou qu'« ils s'accordent un dernier caprice ». Bien trop souvent, les aînés sont considérés comme un fardeau et les soins qui leur sont donnés, comme un gaspillage de ressources limitées qu'on ferait mieux de réserver à des personnes plus jeunes ayant un plus grand potentiel.

La stigmatisation se reflète également dans les conditions de vie imposées à beaucoup d'adultes âgés ayant une maladie mentale, les traitements thérapeutiques cédant la place aux médicaments en doses excessives, à l'immobilisation et à la prestation de services ne répondant qu'aux besoins les plus élémentaires de garde. Le fait de « parquer » de très nombreux aînés au moindre coût possible est sans doute la manifestation la plus odieuse d'une attitude qui nie la valeur des personnes âgées ayant une maladie mentale.

Comme nous le mentionnons ailleurs dans le présent rapport, l'un des principaux éléments du mandat de la Commission canadienne de la santé mentale, dont nous proposons la création, consistera à lancer une campagne très dynamique de 10 ans contre la stigmatisation. L'un des objectifs essentiels d'une telle campagne doit être de changer l'attitude du public envers les aînés ayant une maladie mentale.

## 7.5 CONCLUSION

Plusieurs membres du Comité sont eux-mêmes des adultes âgés. Nous espérons qu'en attirant l'attention sur les lacunes du système de santé mentale qui touchent les aînés et en formulant des recommandations visant le changement et l'amélioration, nous assurerons un avenir plus sûr à nous-mêmes, à nos enfants et à nos petits-enfants. En allant de l'avant, nous nous inspirons des aînés eux-mêmes puisque, pour reprendre les propos de Charmaine Spencer :

*... des aînés ont signalé que, au cours de leur vie, l'information, l'éducation et l'évolution sociales ont permis de faire la lumière sur des questions qui, autrefois, étaient stigmatisées, cachées, taboues, comme le cancer, le divorce, la grossesse et les troubles de développement. Ils se demandent pourquoi cela n'est pas possible dans leur cas aussi<sup>297</sup>.*

Le Comité espère que les travaux de la Commission canadienne de la santé mentale contribueront aussi à cette « normalisation ».

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<sup>297</sup> 8 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/20ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).



## CHAPITRE 8: MILIEU DE TRAVAIL ET EMPLOI

C'est dans le travail que les dimensions humaine et économique de la santé mentale et de la maladie mentale se manifestent le plus nettement. D'une part, le travail peut contribuer de façon tout à fait constructive au bien-être mental, car c'est du travail que nous tirons une bonne partie de notre sentiment d'intégration sociale. Comme Merv Gilbert, psychologue à l'Unité d'évaluation en santé mentale et de consultation communautaire au département de psychiatrie de l'Université de la Colombie-Britannique, l'a expliqué au Comité :

**On a également constaté que le travail aide les personnes souffrant de maladie mentale à se rétablir.**

*Le travail procure un sentiment de structure, une valeur sociale, des soutiens sociaux, un endroit où aller à l'extérieur de la maison[...] et il procure également un revenu, et nous savons que cela favorise la santé mentale<sup>298</sup>.*

On a également constaté que le travail aide les personnes souffrant de maladie mentale à se rétablir. Celles qui ont un emploi sont hospitalisées moins souvent et pour moins longtemps et leur qualité de vie s'en trouve améliorée. Les enquêtes montrent que la plupart des personnes qui souffrent de maladie mentale grave désirent travailler et que c'est là une de leurs priorités.

**On estime que jusqu'à 90 p. cent des personnes ayant une maladie mentale grave ne peuvent se trouver un emploi.**

Mais c'est rarement le cas. En fait, on estime que jusqu'à 90 p. cent des personnes ayant une maladie mentale grave ne peuvent se trouver un emploi<sup>299</sup>. Par ailleurs, comme elles sont exclues de la population active, elles dépendent souvent des programmes de sécurité du revenu pour joindre les deux bouts. Le chômage mène à l'appauvrissement et à un engagement social moindre, ce qui aggrave les troubles physiques et mentaux. Il contribue également à un sentiment d'inutilité et à la dépression, ce qui peut conduire à la toxicomanie.

Cependant, si la participation à la population active peut contribuer à un bon état mental, elle peut également susciter des problèmes mentaux, notamment le stress, la dépression et les troubles anxieux. M. Gilbert a précisé :

*Nous nous retrouvons donc devant l'un des paradoxes fondamentaux : le travail est bon pour la santé mentale, et le travail peut vous rendre fou<sup>300</sup>.*

<sup>298</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>299</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie, (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.1, p. 117.

<sup>300</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

Les questions entourant la santé mentale et le travail sont complexes et présentent bien des facettes. Comme la professeure Romaine Malenfant de l'Université du Québec en Outaouais l'a expliqué au Comité :

*De plus en plus, les recherches démontrent que, non seulement il faut contrer l'absence de travail ou le chômage pour préserver la santé mentale, mais qu'il faut également préserver la qualité du travail pour que le travail joue pleinement son rôle dans la construction de l'identité et l'actualisation de ses pleines capacités<sup>301</sup>.*

## 8.1 COMPRENDRE LES CONSÉQUENCES DES MALADIES MENTALES SUR LE PLAN HUMAIN EN MILIEU DE TRAVAIL

### 8.1.1 Les nombreux facteurs qui contribuent au déclenchement d'une maladie mentale

À propos des liens complexes entre le travail et la santé mentale, le professeur Marc Corbière, de l'Institut de recherche en promotion de la santé de l'Université de Colombie-Britannique, a déclaré au Comité :

**Il n'y a malheureusement aucun consensus scientifique sur la façon de définir et de mesurer un milieu de travail psychosocial à risque élevé.**

*[I]l n'est pas toujours possible d'établir un lien de causalité entre les problèmes de santé mentale et le milieu de travail. Parfois, les problèmes de santé mentale peuvent découler de facteurs liés à la fois à la vie professionnelle et à la vie personnelle<sup>302</sup>.*

Dans un article récent intitulé « Nature and Prevalence of Mental Illness in the Workplace », Carolyn Dewa et ses collègues expliquent :

Le visage de la santé mentale au travail devient de plus en plus flou. Il y a un lien manifeste entre la maladie mentale chez les travailleurs et le stress lié au travail. Ces deux phénomènes sont de plus susceptibles d'être reliés au type de travail, au milieu de travail et au sexe du travailleur.

Il semble également que la maladie mentale et les troubles physiques soient associés. Pourtant, rares sont les études qui ont traité de la manière dont ces divers facteurs expliquent la prévalence des troubles

<sup>301</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>302</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

mentaux chez les travailleurs. Plus rares encore sont celles qui ont traité de leurs apports relatifs à l'incapacité en milieu de travail<sup>303</sup>.

Les auteurs notent que de nombreux facteurs contribuent au développement de maladies mentales comme la dépression, mais que personne ne sait vraiment en quoi elles sont reliées :

Pourtant, les modèles étiologiques les plus avancés de la dépression chez l'adulte comprennent des facteurs liés à la vulnérabilité génétique, ainsi que des facteurs de développement, des facteurs neurobiologiques, des expériences pendant l'enfance, des événements marquants, des situations chroniques (milieu de travail stressant, etc.) et la présence d'autres désordres[...] On comprend mal encore le poids de chacun de ces facteurs et leur interaction<sup>304</sup>.

Il y a bien des façons de classer les facteurs de risque contribuant à l'apparition d'une maladie mentale. Dans son témoignage devant le Comité, Lucie France Dagenais, chercheuse à la Commission des droits de la personne et des droits de la jeunesse au Québec, a cerné deux grandes catégories de facteurs de risque :

*Tout d'abord ceux qui sont reliés aux relations sociales au travail. Cela inclut la violence, le harcèlement, l'absence d'appui social et les mauvaises relations au travail. La deuxième catégorie comprend ceux que l'on retrouve dans l'organisation du travail et qui sont beaucoup moins connus sur une base d'analyse. Nous avons repéré l'intensification du travail, l'absence de marge de manœuvre, les horaires atypiques, l'absence de reconnaissance, l'absence de groupes d'expression, l'avancement au mérite et la flexibilité<sup>305</sup>.*

Toutefois, comme Michel Vézina et ses collègues le signalent dans un article récent, il n'y a malheureusement aucun consensus scientifique sur la façon de définir et de mesurer un milieu de travail psychosocial à risque élevé. Pour eux, les facteurs psychosociaux désignent tous les facteurs organisationnels et les relations interpersonnelles en milieu de travail qui peuvent avoir une influence sur l'état de santé. Parmi les facteurs qui permettent d'établir la nature stressante d'une situation de travail, ils citent :

**Il importe de reconnaître que ce manque de compréhension des liens entre le travail et la maladie mentale n'est pas propre au milieu de travail; il est également présent chez les professionnels de la santé.**

[...] le contrôle (latitude, participation, utilisation et perfectionnement des compétences), la charge de travail (quantité, complexité et délai), les rôles (conflit et ambiguïté), les relations interpersonnelles (appui

<sup>303</sup> C. S. Dewa, A. Lesage, P. Goering et M. Caveen, (2004), document de discussion : « Nature and Prevalence of Mental Illness in the Workplace ». *HealthcarePapers*, vol. 5, n° 2, p. 18 [traduction].

<sup>304</sup> *Ibid.*, p. 20.

<sup>305</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

social, harcèlement et reconnaissance), les perspectives professionnelles (promotion, précarité et rétrogradation), la culture ou le climat organisationnel (communication, structure hiérarchique et équité) et l'interaction entre travail et vie privée<sup>306</sup>.

Les attitudes négatives envers la maladie mentale demeurent répandues dans la société et peuvent exacerber les difficultés créées par les conditions de travail. Les personnes ayant des troubles mentaux peuvent susciter des craintes chez leurs employeurs et leurs collègues, ces derniers pouvant estimer qu'elles sont non spécialisées, improductives, non fiables et parfois même violentes<sup>307</sup>. Ces perceptions non justifiées peuvent contribuer à des hésitations au moment d'embaucher quelqu'un ayant eu des troubles mentaux, ou de limiter l'avancement professionnel de cette personne si un épisode de maladie mentale est révélé. Ceux qui ont le courage de « reconnaître publiquement » leurs problèmes au travail risquent également de perdre leur emploi.

Il importe de reconnaître que ce manque de compréhension des liens entre le travail et la maladie mentale n'est pas propre au milieu de travail; il est également présent chez les professionnels de la santé. Pour Merv Gilbert :

*Avec tout le respect que je leur dois, la plupart des fournisseurs de soins en santé mentale n'ont aucune idée de ce qui se passe en milieu de travail. En général, les médecins qui ont devant eux un patient en pleurs, atteint d'un trouble connu, qui demande s'il doit rester au travail, retourner au travail, qui veut savoir comment composer avec ses problèmes en milieu de travail, sont bien souvent mal informés. Ils ont peut-être devant eux une description de poste mal rédigée, s'ils sont chanceux, pour déterminer si une personne devrait travailler, quelles mesures d'adaptation devraient être prises, et quels enjeux devraient être abordés. Par conséquent, j'insiste sur le fait que nous devons également instruire les intervenants du système de soins de santé<sup>308</sup>.*

### 8.1.2 La nature épisodique de la maladie mentale

La nature épisodique et cyclique de la plupart des maladies mentales est un autre facteur qui complique l'évaluation de la santé mentale en milieu de travail. Et il devient d'autant plus difficile d'apporter les aménagements

**La nature épisodique et cyclique de la plupart des maladies mentales est un autre facteur qui complique l'évaluation de la santé mentale en milieu de travail.**

nécessaires au travail pour les personnes ayant une maladie mentale. Contrairement aux autres groupes de personnes handicapées, les personnes ayant une maladie mentale sont rarement souffrantes de manière continue; elles alternent entre des périodes de maladie et

<sup>306</sup> M. Vézina, R. Bourbonnais, C. Brisson et L. Trudel (2004), document de discussion : « Workplace Prevention and Promotion Strategies », *HealthcarePapers*, vol. 5, n° 2, p. 34.

<sup>307</sup> Association des psychiatres du Canada (2005), La maladie mentale et le travail, [http://www.cpa-apc.org/MIAW/pamphlets/Work\\_fr.asp](http://www.cpa-apc.org/MIAW/pamphlets/Work_fr.asp).

<sup>308</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

des périodes de bien-être. Lorsqu'elles n'ont pas de symptômes, elles sont généralement en mesure de travailler et d'effectuer les tâches courantes de la vie quotidienne. Lors des épisodes de troubles psychiatriques, elles deviennent alors parfois incapables de fonctionner suffisamment bien pour conserver un travail régulier à temps plein.

Compte tenu de la nature cyclique, épisodique et imprévisible des maladies mentales graves, il peut être impossible d'acquérir une expérience professionnelle suffisamment longue et stable. Il est particulièrement difficile de retrouver un emploi lorsque son curriculum indique des périodes de chômage inexpliquées.

### **8.1.3 La diversité des liens entre maladie mentale et travail**

Les différentes catégories de personnes atteintes de maladies mentales connaissent chacune des difficultés particulières pour ce qui est de l'emploi.

Dans bien des cas, les troubles mentaux ont tendance à se déclencher à la fin de l'adolescence ou au début de la vie adulte, à un moment où les études et la formation ne sont pas encore terminées. Le processus de préparation à l'emploi est interrompu et, bien souvent, il ne redémarre jamais. Les jeunes touchés sont très désavantagés; l'absence de compétences et de qualifications constitue un important obstacle à leur emploi futur<sup>309</sup>.

Il arrive aussi que la carrière soit interrompue par des maladies mentales graves ou une toxicomanie. Beaucoup ne retrouvent pas de place sur le marché du travail. Pour les personnes qui ont un travail, les périodes de retrait de la population active pour cause de maladie mentale les empêchent souvent de retrouver leur emploi.

Trois grands obstacles s'appliquent dans ce cas. Premièrement, les personnes visées peuvent faire l'objet de discrimination de la part de leur employeur ou de leurs collègues, ou des deux. Deuxièmement, elles peuvent avoir besoin d'un assouplissement de leurs conditions de travail que les employeurs hésitent à accorder ou ne savent pas comment accorder. Troisièmement, celles qui se sont retrouvées hors du marché du travail pendant de longues périodes ne possèdent probablement pas le type de compétences, de qualifications et d'expérience professionnelle qui intéressent les employeurs.

Enfin, il existe un large groupe de personnes actuellement employées mais dont la productivité est amoindrie à des degrés divers par des difficultés sur le plan de la santé mentale, état souvent désigné de « présentisme ».

Cette diversité signifie que la question de la santé mentale, de la toxicomanie et du travail doit être étudiée selon différents angles : permettre à ceux qui n'ont jamais eu de travail d'obtenir un emploi; permettre à ceux qui ont perdu leur travail en raison d'une maladie mentale ou d'une toxicomanie de réintégrer le marché du travail et étudier la façon dont la maladie mentale ou la toxicomanie nuit à ceux ayant actuellement un emploi.

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<sup>309</sup> Voir chapitre 6, « Les enfants et les adolescents ».

#### 8.1.4 Bien des points de recherche restent sans réponse

À la lumière des recherches actuelles, on se rend vite compte que l'on sait peu de choses des maladies mentales au travail et des troubles liés au stress, que ce soit pour définir l'ampleur du problème ou d'établir les meilleures façons de le gérer<sup>310</sup>. Dans un article récent, Elliot Goldner et ses collègues notaient que :

Beaucoup de travaux de recherche sur la santé en milieu de travail ont porté sur la gestion de l'incapacité, le retour au travail et le traitement. Pour la plupart, toutefois, ces travaux ne traitaient pas directement des problèmes de santé mentale mais étaient axés sur divers problèmes de santé physique que l'on trouve en milieu de travail (problèmes de dos et autres problèmes musculo-squelettiques, blessures au cerveau, maladies cardiaques et maladies rhumatismales chroniques)<sup>311</sup>.

Ces travaux montrent également que la pauvreté des recherches dans le domaine de la santé mentale au travail n'est pas un phénomène nouveau.

**À la lumière des recherches actuelles, on se rend vite compte que l'on sait peu de choses des maladies mentales au travail et des troubles liés au stress, que ce soit pour définir l'ampleur du problème ou d'établir les meilleures façons de le gérer.**

Dans un article publié en 1993, Rachel Jenkins se demandait pourquoi la santé mentale au travail faisait l'objet de si peu de recherches. Plus de dix ans plus tard, la même question se pose. Il existe beaucoup de lacunes dans nos connaissances. On sait peu de choses des pratiques à suivre pour gérer les incapacités liées aux troubles mentaux les plus fréquents (dépression, troubles anxieux et désordres liés à la toxicomanie). Même si l'on dispose de certains renseignements pouvant aider les personnes souffrant de désordres mentaux graves à obtenir un emploi, on ignore souvent comment les aider à garder leur emploi. De plus, on ne sait rien des facteurs systémiques qui influent sur la gestion des incapacités et sur le retour au travail (programmes d'aide aux employés et règlements sur l'assurance-invalidité) des personnes ayant des troubles mentaux<sup>312</sup>.

Autre fait important, les spécialistes des divers domaines ne parlent pas toujours le même langage, ce qui nuit encore plus à l'intégration des recherches en santé mentale au travail. C'est ce qu'Aldred H. Neufeldt a bien fait valoir :

Une grande difficulté vient de ce que les connaissances existantes présentent ce que l'on pourrait appeler le « syndrome des îlots ». Les

<sup>310</sup> E. Archambault, G. Cote et Y. Gingras (2003), « Bibliometric Analysis of Research on Mental Health in the Workplace in Canada ». Cité dans une recherche menée pour le Comité par Neasa M. Martin and Associates, juin 2005.

<sup>311</sup> E. Goldner, D. Bilsker, M. Gilbert, L. Myette, M. Corbiere et C. S. Dewa (2004), document de discussion : « Disability Management, Return to Work and Treatment », Healthcare Papers, vol. 5, no 2, p. 77 [traduction].

<sup>312</sup> *Ibid.*, p. 86.

différents types de recherches sont publiés dans différents types de journaux, et les références croisées sont peu fréquentes. Les revues d'épidémiologie examinent la relation entre le fonctionnement et le handicap psychiatrique. Les ouvrages de santé et de psychologie du travail portent sur des sujets comme les éléments de stress au travail, la santé, le rendement et l'absentéisme. Les documents sur la réadaptation et la psychiatrie analysent les traitements particuliers de maladies psychiatriques, ainsi que l'efficacité d'interventions comme les hospitalisations de courte et de longue durée, l'emploi assisté, la gestion de cas, etc.<sup>313</sup>.

Il est donc encore plus difficile pour les employeurs et pour les employés de concevoir des pratiques exemplaires à partir d'examens complets de la littérature scientifique.

## 8.2 L'IMPACT ÉCONOMIQUE DE LA SANTÉ MENTALE EN MILIEU DE TRAVAIL

Nous le répétons, la recherche dans le domaine de la santé mentale en milieu de travail présente beaucoup de lacunes de taille. Dans son rapport intérimaire, le Comité notait l'absence de statistiques probantes sur la prévalence des maladies mentales et des toxicomanies en milieu de travail<sup>314</sup>.

**Les prestations d'invalidité attribuables à des maladies mentales dépassent maintenant les prestations relatives aux maladies cardiovasculaires, au titre de la catégorie de coûts d'invalidité qui augmente le plus rapidement Canada. À l'heure actuelle, les maladies mentales et la toxicomanie représentent de 60 à 65 p.100 de toutes les demandes de prestations d'invalidité chez quelques employeurs canadiens et américains.**

Néanmoins, le Comité a été informé que les prestations d'invalidité attribuables à des maladies mentales dépassent maintenant les prestations relatives aux maladies cardiovasculaires, au titre de la catégorie de coûts d'invalidité qui augmente le plus rapidement Canada. À l'heure actuelle, les maladies mentales et la toxicomanie représentent de 60 à 65 p.100 de toutes les demandes de prestations d'invalidité chez quelques employeurs canadiens et américains<sup>315</sup>.

**Les maladies mentales et la toxicomanie arrivent au premier et au deuxième rang des causes d'invalidité au Canada, aux États-Unis et en Europe de l'Ouest.**

<sup>313</sup> A. H. Neufeldt (2004), document de discussion : « What Does It Take to Transform Mental Health Knowledge into Workplace Practice? Towards a Theory of Action », *Healthcare Papers*, vol. 5, no 2, p. 123, [traduction].

<sup>314</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.1, p. 116. Voir aussi Dewa et al. (2004), p. 13.

<sup>315</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.4, p.124.

Mme Dewa et ses collègues ont signalé que :

Depuis quelques années, le nombre des prestations d'invalidité attribuables à des maladies mentales augmente sans cesse. Entre 1989 et 1994, selon la Health Insurance Association of America (1995), les prestations de ce type ont doublé. Au Canada, l'invalidité à court et à long terme liée à des troubles mentaux représente jusqu'à un tiers des prestations et 70 p. cent environ de l'ensemble des coûts — soit de 15 à 33 milliards de dollars par an<sup>316</sup>.

Comparativement à toutes les autres maladies (comme le cancer et les maladies du cœur), les maladies mentales et la toxicomanie arrivent au premier et au deuxième rang des causes d'invalidité au Canada, aux États-Unis et en Europe de l'Ouest. Parmi les dix principales causes d'invalidité dans le monde, cinq sont des troubles mentaux : dépression unipolaire, alcoolisme, trouble bipolaire, schizophrénie et trouble obsessionnel-compulsif<sup>317</sup>.

Qui plus est, comme cela a été signalé lors de la Global Business and Economic Roundtable on Addiction and Mental Health, les maladies mentales — dépression, troubles anxieux et toxicomanie — sont concentrées chez les hommes et les femmes les plus aptes au travail et parmi les personnes ayant entre 15 et 24 ans<sup>318</sup>. Les Canadiens les plus susceptibles d'avoir une maladie mentale sont au cœur de notre population active et de nos consommateurs.

**Les Canadiens les plus susceptibles d'avoir une maladie mentale sont au cœur de notre population active et de nos consommateurs.**

Les troubles mentaux, non contrôlés et handicapants, nuisent à la capacité d'un segment important de notre population de contribuer activement à l'économie. L'innovation et la productivité sont des facteurs de plus en plus cruciaux pour la croissance et la prospérité économiques. Les troubles mentaux devraient être reconnus comme une source importante d'incapacité parmi ceux sur lesquels nous comptons pour nous assurer ces niveaux critiques de croissance et de compétitivité.

La productivité est touchée à la fois par le « présentéisme » — journées pendant lesquelles une personne est présente au travail mais ne peut donner tout son potentiel — et l'absentéisme — journées pendant lesquelles l'employé ne se présente pas au travail. La maladie mentale et la toxicomanie comptent parmi les plus importantes causes d'absentéisme et de présentéisme dans le monde entier : dans son rapport publié en 1998, l'Organisation mondiale de la santé affirmait que le nombre de journées de travail perdues à cause de troubles mentaux dépasse celui des journées perdues à cause de maladies physiques.

<sup>316</sup> Dewa et al. (2004), p. 22, [traduction].

<sup>317</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.3, p. 121.

<sup>318</sup> Global Business and Economic Roundtable on Addiction and Mental Health (2006), « Employers Getting Started — The Road to Mental Health and Productivity, Module Trois: The Demographics and Distribution of Mental Illness: Mostly an Economic, Business and Labour Cost — Health Care Costs Less Than Productivity Loss ».

Au Canada, 20 p. cent des heures normales de travail des employés souffrant d'une maladie mentale ou d'une toxicomanie non dépistée ne sont pas productives parce qu'elles ne sont pas travaillées. Ce pourcentage est quatre fois plus élevé que chez leurs collègues de travail<sup>319</sup>.

Mme Dewa et ses collègues ont signalé que :

On a observé qu'une proportion significative du problème que constituent les troubles mentaux provient des journées de présentéisme... On distingue ainsi les troubles mentaux des maladies physiques de type chronique. Ces dernières sont associées à des journées d'incapacité totale, tandis que les troubles psychiatriques se traduisent le plus souvent par une incapacité partielle; en fait, ces derniers ont causé 23 fois plus de journées d'incapacité partielle que de journées d'incapacité totale<sup>320</sup>.

En 1998, on a chiffré à 8,1 milliards de dollars environ la productivité perdue au Canada, uniquement à cause des maladies mentales. Plus récemment, on a évalué, en tenant compte de la toxicomanie, que l'économie canadienne perd quelque 33 milliards de dollars par an. Ceci correspond à 19 p. cent des profits combinés de toutes les entreprises canadiennes et à 4 p. cent de la dette nationale<sup>321</sup>.

Ce sont essentiellement sur les employeurs et les employés que retombent les conséquences financières des troubles mentaux au Canada, par le truchement des dépenses de fonctionnement, des charges salariales, des diverses cotisations et des faux frais. Quelques grandes entreprises canadiennes ont expliqué l'impact financier des troubles mentaux de leurs employés dans des déclarations présentées à l'occasion de la Global Business and Economic Roundtable on Addiction and Mental Health<sup>322</sup> :

- À la CIBC, en moyenne 95 journées de travail sont perdues à cause des maladies mentales, contre 40 à cause d'autres types de maladie.
- La Great-West, Compagnie d'assurance-vie estime que 30 p. cent des demandes d'assurance-invalidité concernent des maladies mentales et que, pour les 70 p. cent restants, un quart ou plus concernent des maladies mentales comme diagnostic secondaire ou sous-jacent.

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<sup>319</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.3, p. 121.

<sup>320</sup> Dewa et al. (2004), p. 19, [traduction].

<sup>321</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.3, p. 121

<sup>322</sup> Global Business and Economic Roundtable on Addiction and Mental Health (2006), Module trois.

### 8.2.1 L'impact des tendances économiques mondiales sur la santé mentale au travail

Il est crucial de tenir compte de deux tendances, soulignées par la Global Business and Economic Roundtable on Addiction and Mental Health, dans la façon dont il faut aborder les questions de santé mentale en milieu de travail en ce XXI<sup>e</sup> siècle<sup>323</sup>.

La première tendance — l'importance croissante du savoir et des compétences intellectuelles en général pour l'économie — constitue une excellente raison de s'attaquer aux problèmes de santé mentale en milieu de travail.

La seconde tendance — les exigences imposées par une économie devant être concurrentielle sur le plan international et tirée par les investissements — renforce la première tendance de bien des façons, mais elle peut également être à la source de graves risques pour la santé mentale des travailleurs, notamment parce qu'elle accroît le niveau de stress.

La plupart des nouveaux emplois exigent aujourd'hui des capacités plus cérébrales que manuelles, autrefois si importantes. S'il est vrai (ce qui est quasi certain) que nous voyons l'émergence d'une économie du savoir intellectuel, les questions de santé mentale doivent occuper la première place dans les affaires économiques du Canada.

**S'il est vrai (ce qui est quasi certain) que nous voyons l'émergence d'une économie du savoir intellectuel, les questions de santé mentale doivent occuper la première place dans les affaires économiques du Canada.**

Les plus hauts échelons des sociétés canadiennes sont de plus en plus conscients de cette nouvelle réalité. Selon Gordon Nixon, président et chef de la direction, RBC Groupe financier, nous aurions une économie de performance mentale dans laquelle la capacité d'innovation — de pensée créatrice — des employés est un atout de taille. Pour Robert MacLellan, vice-président exécutif et directeur principal des investissements au Groupe financier Banque TD, la santé mentale revêt dans ce contexte une grande importance, car, selon lui, une forte prévalence de maladies mentales (désordres cérébraux) prive notre économie d'employés productifs et novateurs<sup>324</sup>.

**La nouvelle économie a donné naissance à une convergence coûteuse — l'avènement d'une économie cérébrale à une époque où les désordres cérébraux deviennent la principale cause d'incapacité dans la main-d'œuvre active.**

L'honorable Michael Wilson, ancien conseiller spécial auprès du ministre de la Santé pour les questions de santé mentale au sein du gouvernement fédéral, a formulé ce que la Global Business and Economic Roundtable on Addiction and Mental Health a qualifié de « principe Wilson » :

<sup>323</sup> Global Business and Economic Roundtable on Addiction and Mental Health (2006), « Employers Getting Started — The Road to Mental Health and Productivity, Module deux: The Building Blocks of Productive Capacity in a Brain-Based Economy — Setting the Stage for Mental Health in the Workplace ».

<sup>324</sup> *Ibid.*

Nous avons fait d'énormes progrès dans la prévention des blessures et des maladies physiques au travail. Les entreprises auxquelles je suis associé tirent une grande fierté de leurs résultats sur le plan de la sécurité. J'encourage fortement les employeurs à miser sur ces réalisations.

Il serait dommage de défaire ces 30 années de progrès réalisés sur le plan de la santé et de la sécurité physiques en laissant se perdre une énorme capacité productrice parce que l'on n'aura pas traité les maladies mentales, surtout la dépression<sup>325</sup>.

La nouvelle économie a donné naissance à une convergence coûteuse — l'avènement d'une économie cérébrale à une époque où les désordres cérébraux deviennent la principale cause d'incapacité dans la main-d'oeuvre active.

Les incidences de cette nouvelle réalité ne se manifestent cependant pas toujours immédiatement, surtout compte tenu de la seconde tendance mentionnée. Sous les intenses pressions, surtout venant des investisseurs, qu'elles subissent pour adopter une approche valeur, les entreprises doivent parfois licencier du personnel et s'efforcer de « faire plus avec moins ». Outre les énormes coûts sur le plan humain que les licenciements massifs ont représentés pour les intéressés, il est également important de reconnaître les conséquences éventuelles à plus long terme de cette stratégie pour les entreprises elles-mêmes.

**Les arguments prônant des milieux de travail propices à une bonne santé mentale sont donc irréfutables.**

Dans une économie qui mise essentiellement sur la productivité et l'innovation, le déploiement prudent de capital humain est d'une importance critique pour la compétitivité. Le capital humain est en fait une capacité réellement productrice. Dans une économie axée sur la performance mentale des travailleurs, la capacité de penser, de se concentrer et d'innover est cruciale. Les stratégies qui sapent cette capacité nuiront probablement à long terme aux sociétés qui les pratiquent.

Les arguments prônant des milieux de travail propices à une bonne santé mentale sont donc irréfutables, étant donné que de tels milieux se traduiront par une hausse de la productivité, laquelle compensera les coûts des investissements nécessaires pour réduire de façon significative les facteurs pouvant nuire à la santé mentale des travailleurs.

### 8.3 INITIATIVES À PARTIR DU LIEU DE TRAVAIL

Il y a deux grandes catégories d'interventions sur le plan de la santé mentale au travail. Tout d'abord, les mesures de prévention primaire, qui visent à éliminer, ou du moins à atténuer, les facteurs nuisant à la santé mentale des travailleurs. Ensuite, il existe une panoplie de stratégies d'intervention secondaire conçues essentiellement pour réduire les effets du stress professionnel en améliorant la capacité des individus à s'adapter au stress et à le gérer.

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<sup>325</sup> *Ibid.* [traduction]

### 8.3.1 Prévention primaire

Il semblerait que les approches organisationnelles bien structurées donnent des effets plus notables et plus durables que les stratégies d'intervention secondaire s'adressant aux individus<sup>326</sup>. D'après les recherches sur l'intervention de prévention, il faut s'attaquer à certaines causes liées au travail pour réduire ou éliminer le stress. Deux modèles de risques cernent les relations psychosociales et interpersonnelles qui contribuent à rendre les gens malades : 1) le modèle « exigences du travail-contrôle-soutien » de Karasek et 2) le modèle « déséquilibre effort/récompense » de Siegrist.

Le modèle « exigences du travail-contrôle-soutien » s'appuie sur le fait qu'une situation professionnelle caractérisée par de fortes exigences psychologiques combinées à un manque de liberté décisionnelle accroît le risque de susciter une situation propice aux maladies mentales ou physiques<sup>327</sup>. Le modèle « déséquilibre effort/récompense » s'appuie sur le fait qu'une situation professionnelle caractérisée par des efforts importants combinés à de maigres récompenses peut s'accompagner de réactions émotionnelles et physiologiques qui peuvent nuire à la santé mentale<sup>328</sup>.

**D'après les recherches sur l'intervention de prévention, il faut s'attaquer à certaines causes liées au travail pour réduire ou éliminer le stress.**

**Les interventions axées sur l'organisation du travail peuvent présenter d'énormes avantages, sur le plan surtout de l'absentéisme et de la dépression et même du bien-être et de la productivité.**

Si c'est le « contrôle » qui est au coeur du modèle de Karasek, c'est la « réciprocité sociale » (c.-à-d. la possibilité d'avoir accès à des avantages légitimes, dûment gagnés dans l'exercice du travail) qui est le concept clé du modèle de Siegrist. Ce dernier est particulièrement bien conçu pour mesurer l'incidence, sur la santé mentale, d'un nouveau phénomène survenu au cours des dix dernières années, à savoir la précarité de l'emploi<sup>329</sup>.

Diverses études ont dégagé les caractéristiques d'un milieu de travail propice à la fois à la rentabilité et à une meilleure santé mentale, à savoir la sécurité de l'emploi, les équipes autogérées et la prise de décisions décentralisée, une formation approfondie, des distinctions hiérarchiques moindres et une atténuation des barrières à la communication, dans tout l'organisme, de l'information financière et de l'information sur le rendement. Vézina et ses collègues ont mentionné des études qui dégagent cinq facteurs nécessaires au succès d'un projet d'intervention primaire. Il s'agit :

du soutien de la haute direction et de la participation de tous les niveaux hiérarchiques; de la participation des employés aux discussions des problèmes et aux éventuelles solutions; de l'identification préliminaire des effectifs à risque compte tenu de modèles théoriques validés ou de leur manifestations connexes; de

<sup>326</sup> Vézina et al. (2004), p. 39.

<sup>327</sup> *Ibid.*, p. 34.

<sup>328</sup> *Ibid.*, p. 36

<sup>329</sup> *Ibid.*

l'application rigoureuse des changements nécessaires dans les effectifs ciblés et de la gestion sur place des procédures et des changements<sup>330</sup>.

Des études ont montré que, si ces facteurs sont en place, les interventions axées sur l'organisation du travail peuvent présenter d'énormes avantages, sur le plan surtout de l'absentéisme et de la dépression et même du bien-être et de la productivité. Malgré ces preuves empiriques appuyant l'impact de ces modèles sur la santé, peu de stratégies globales d'intervention en milieu de travail ont été mises en place.

La Global Business and Economic Roundtable on Addiction and Mental Health a cerné dix pratiques ou comportements de gestion qui peuvent précipiter ou aggraver les problèmes de santé mentale au travail :

1. Imposer des exigences déraisonnables aux subordonnés et retenir de l'information qui les concerne au premier chef pour l'exercice de leurs fonctions.
2. Refuser de donner aux employés une latitude raisonnable sur leurs moyens de travail quotidiens.
3. Ne pas reconnaître la contribution et les réalisations des employés.
4. Donner une charge de travail constamment trop lourde accompagnée de délais trop courts.
5. Créer un doute perpétuel, si bien que les employés ne savent jamais ce qui va se produire autour d'eux.
6. Permettre à la méfiance de s'enraciner. Les manigances au bureau nuisent au comportement constructif.
7. Tolérer, et même encourager, l'ambiguïté dans les orientations, les politiques, les fonctions et les attentes.
8. Pratiques de gestion du rendement laissant à désirer — surtout pour ce qui est des évaluations de rendement des employés — même quand elles sont favorables — si bien que les employés ignorent leur rôle dans l'entreprise à court ou à moyen terme.
9. Manque de communication dans les deux sens dans l'organisme
10. Des gestionnaires qui balaient du revers de la main les préoccupations des employés à propos de leur charge de travail<sup>331</sup>.

Le Comité convient avec la Table ronde qu'une stratégie d'intervention primaire réussie doit tenter de modifier ces pratiques néfastes et recommande donc :

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<sup>330</sup> Vézina et al. (2004), p. 39-40. [traduction]

<sup>331</sup> Global Business and Economic Roundtable on Addiction and Mental Health (2004), Roundtable « Roadmap to Mental Disability Management ». [traduction]

Que la Commission canadienne de la santé mentale (voir le Chapitre 16) travaille avec les employeurs à l'élaboration et à la diffusion de pratiques de gestion exemplaires propices à la santé mentale au travail.

### 8.3.2 Intervention secondaire

Il faut noter trois types d'intervention secondaire : 1) la gestion des limitations fonctionnelles; 2) l'aménagement du lieu de travail et 3) les programmes d'aide aux employés (PAE).

#### 8.3.2.1 La gestion des limitations fonctionnelles

La gestion des limitations fonctionnelles est largement répandue comme moyen de réintégration professionnelle des personnes ayant un handicap physique. Parmi les facteurs propices à cette réintégration se trouvent la participation de l'employeur, un climat d'entraide et la coopération entre syndicats et patronat. Bien que courants dans les cas d'incapacités physiques, les programmes de gestion des limitations fonctionnelles sont relativement nouveaux dans le domaine de la santé mentale, et les études sur le sujet sont trop peu nombreuses pour que l'on puisse en établir l'efficacité<sup>332</sup>.

**Faute de sensibilisation aux maladies mentales des employés, des gestionnaires et des superviseurs, les problèmes de santé mentale et de toxicomanie au travail ne peuvent être rapidement détectés et réglés.**

La gestion des limitations fonctionnelles en milieu de travail peut être complexe, étant donné qu'il s'agit d'une responsabilité que se partagent le travailleur, les superviseurs et les gestionnaires, les programmes d'aide aux employés, les gestionnaires de ressources humaines et le système de santé public<sup>333</sup>. Faute de sensibilisation aux maladies mentales des employés, des gestionnaires et des superviseurs, les problèmes de santé mentale et de toxicomanie au travail ne peuvent être rapidement détectés et réglés.

Une autre difficulté vient du fait que le système de soins de santé et les milieux de travail sont très différents, sur le plan des cultures, des langues, des pratiques et des priorités. Les cadres conceptuels divergents utilisés par les professionnels de la santé au travail et les spécialistes de la santé mentale peuvent nuire à la compréhension, si bien que les services peuvent être mal coordonnés et que la réintégration professionnelle est retardée<sup>334</sup>. Il est donc essentiel de créer des objectifs communs et d'avoir une compréhension et un langage communs pour que l'information et la connaissance puissent être diffusées dans les

<sup>332</sup> Neufeldt (2004).

<sup>333</sup> W. Gnam (2004), « Researcher Response: Research Priorities Are Critical ». *HealthcarePapers*, vol. 5, no 2, p. 91-94.

<sup>334</sup> A. Bender et S. Kennedy (2004), document de discussion : « Mental Health and Mental Illness in the Workplace: Diagnostic and Treatment Issues ». *HealthcarePapers*, vol. 5, no 2, p. 54-67.

différents systèmes. Ce qu'il faut, ce sont des leaders qui connaissent à la fois le domaine de la santé mentale et les questions propres aux employeurs et qui peuvent faciliter l'intégration de systèmes disparates de manière plus efficace avec le temps.

Le Comité recommande donc :

32

**Que le Centre d'échange des connaissances créé dans le cadre de la Commission canadienne de la santé mentale (voir le Chapitre 16) aide employeurs, professionnels de la santé au travail et fournisseurs de soins de santé mentale à élaborer un langage commun, dans le but d'encourager la gestion des limitations fonctionnelles d'ordre mental, et à communiquer les pratiques exemplaires dans le domaine.**

### **8.3.2.2 Aménagement du lieu de travail**

Les aménagements désignent « une ou plusieurs modifications du milieu de travail ou des procédures du milieu de travail qui permettent à une personne ayant des besoins spéciaux d'effectuer une tâche »<sup>335</sup>.

Alors que les personnes ayant une incapacité physique ont peut-être besoin d'une aide matérielle ou de changements structurels du lieu de travail, celles souffrant de troubles mentaux ont le plus souvent besoin d'aménagements sociaux et organisationnels.

**Les aménagements signifient un traitement équitable des personnes ayant un handicap, quels qu'en soient le type et la source.**

Ces aménagements consistent généralement en modifications de la façon dont les choses sont traditionnellement effectuées dans un lieu de travail particulier. Autoriser, par exemple,

quelqu'un ayant une maladie mentale à travailler selon un horaire flexible lui permet d'accéder à un emploi, de la même façon qu'une rampe d'accès permet à une personne handicapée de se déplacer en fauteuil roulant. Ces mesures signifient simplement un traitement équitable des personnes ayant un handicap, quels qu'en soient le type et la source.

**Il n'existe ni liste complète des aménagements dont les personnes ayant des problèmes mentaux ont besoin, ni recherche définissant les meilleures approches en la matière.**

D'après l'Association des psychiatres du Canada<sup>336</sup>, les aménagements devraient être axés sur des mécanismes positifs qui favorisent l'égalité d'emploi et consisteraient à :

- créer un environnement où les aménagements sont établis en fonction des besoins individuels de chaque employé;

<sup>335</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.5.2, p. 135.

<sup>336</sup> *Ibid.*, p. 135.

- respecter le désir de confidentialité de l'employé et déterminer précisément la nature et l'ampleur de la discrétion requise;
- être disposé à se concerter pour résoudre les problèmes;
- donner à l'employé le choix d'accepter les aménagements et être prêt à examiner les plans périodiquement pour s'adapter à l'évolution des besoins de ce dernier;
- appliquer les politiques en vigueur avec souplesse;
- définir concrètement et précisément les aménagements à prendre, de préférence par écrit.

Une autre étude a révélé que, sur une période de dix ans, 240 personnes ayant une maladie mentale grave ont pu garder un emploi rémunérateur en grande partie grâce à des programmes de réintégration professionnelle. Ces personnes ont touché 5 millions de dollars de revenus, versé 1,3 million de dollars d'impôts et fait économiser environ 700 000 \$ au gouvernement en aide sociale. Le résultat net a été une hausse de 2 millions de dollars de la richesse collective<sup>337</sup>.

Selon Mental Health Works, ACSM Ontario<sup>338</sup>, il n'existe ni liste complète des aménagements dont les personnes ayant des problèmes mentaux ont besoin, ni recherche définissant les meilleures approches en la matière. Pour procéder à des aménagements, il faut tenir compte des besoins

**Il importe que toutes les parties se rappellent que la réintégration professionnelle fait partie intégrante du rétablissement des employés ayant un trouble mental.**

individuels des employés et des ressources disponibles pour l'employeur. Quoi qu'il en soit, à mesure que seront éliminées les barrières systémiques, le besoin d'aménagement individuel diminuera. Par exemple, les horaires variables peuvent être à l'avantage de tous les employés, tout en permettant à ceux qui ont une maladie mentale et qui doivent modifier leurs heures de travail de le faire sans avoir à demander d'aménagement particulier.

Le devoir de procéder à des aménagements n'incombe pas uniquement à l'employeur, mais est partagé avec les syndicats. Le Comité est d'avis qu'il est dans l'intérêt de l'employé que patronat et syndicats collaborent pour permettre la réintégration professionnelle grâce à des modifications du poste et autres aménagements. Dans ce contexte, il importe que toutes les parties se rappellent que la réintégration professionnelle fait partie intégrante du rétablissement des employés ayant un trouble mental.

<sup>337</sup> G. Harnois et P. Gabriel (2000), *Mental Health and Work: Impact, Issues and Good Practices*, publication conjointe de l'Organisation mondiale de la santé et de l'Organisation internationale du travail, Genève, p. 19

<sup>338</sup> Mental Health Works, ACSM Ontario. <http://www.mentalhealthworks.ca/index.asp>.

### 8.3.2.2.1 Autres aménagements en matière de santé mentale

Autres possibilités d'aménagement à l'intention des personnes atteintes de maladie mentale :

Horaires de travail souples

- Temps partiel (pour permettre éventuellement à un travailleur de revenir travailler à temps plein)
- Fréquence accrue des pauses

Modification du mode de supervision

- Modifier la façon dont les instructions et la rétroaction sont fournies. Il peut être utile d'écrire les instructions pour aider l'employé à se concentrer sur ses tâches.
- Tenir des rencontres hebdomadaires entre le superviseur et l'employé pour régler les problèmes avant qu'ils ne s'aggravent.

Modification sur le plan de la formation

- Prévoir davantage de temps pour que l'employé apprenne ses tâches.
- Permettre à l'employé d'assister à des cours de formation individualisés.

Modification des fonctions

- Échanger les tâches moins importantes avec d'autres employés.

Modification des locaux ou du lieu de travail

- Permettre à un employé de travailler dans un secteur plus tranquille où il sera moins distrait.
- Permettre à l'employé de travailler chez lui

### 8.3.2.3 Programmes d'aide aux employés (PAE)<sup>339</sup>

Les PAE sont des programmes d'employeur visant à atténuer et à contribuer à éliminer divers problèmes en milieu de travail. La source de ces problèmes peut être personnelle (problèmes juridiques, financiers, conjugaux ou familiaux, maladies et problèmes de santé mentale, y compris la toxicomanie) ou professionnelle (conflit au travail, harcèlement, violence, stress, etc.).

**Les PAE sont devenus le principal mécanisme par lequel les travailleurs canadiens accèdent à des soins en santé mentale et des services de traitement de la toxicomanie**

<sup>339</sup> Cette section est largement inspirée de : Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, p. 134.

Habituellement, les PAE offrent des services de counselling, de diagnostic, d'aiguillage et de traitement. Le personnel responsable possède habituellement un diplôme dans une discipline reliée à la santé mentale ou aux services sociaux (travail social, psychologie, psychiatrie, counselling et/ou thérapie de couple ou familiale). Certains services peuvent aussi être sous-traités à d'autres personnes qualifiées.

Les services des PAE sont offerts dans des organismes privés et publics et habituellement administrés en totale indépendance des autres programmes de l'organisation. La confidentialité est la pierre angulaire d'un PAE efficace. L'anonymat des clients, la confidentialité des entrevues, la tenue, le transfert et la destruction des dossiers sont assujettis aux lois fédérales et provinciales applicables, qui régissent la conduite des conseillers. En règle générale, l'information peut être divulguée par un conseiller de PAE uniquement lorsque le client a rempli un formulaire de consentement signé en toute connaissance de cause et a stipulé quelle information sera communiquée et à qui.

Le Comité a appris que de 60 à 80 p. cent des Canadiens qui travaillent dans une moyenne ou une grande entreprise (comptant plus de 500 employés) ont accès à une forme quelconque de PAE. D'après Rod Phillips, président et directeur général des Consultants Warren Shepell, les PAE sont très efficaces; ils sont devenus le principal mécanisme par lequel les travailleurs canadiens accèdent à des soins en santé mentale et des services de traitement de la toxicomanie :

Dans de nombreux cas, d'après notre expérience, environ 85 p. cent des gens que nous voyons au cours d'une année reçoivent un traitement suffisant dans le cadre des programmes d'aide aux employés et ne nécessitent aucun autre traitement. Environ 15 p. cent des gens sont ensuite aiguillés vers des programmes communautaires ou vers le régime de soins de santé public<sup>340</sup>.

Les PAE misent aussi fortement sur la prévention. Le gros du travail effectué avec les employeurs porte sur le mieux-être et sur d'autres programmes favorisant un cadre de travail sain et propice à une bonne santé mentale.

Les PAE sont très largement répandus en Amérique du Nord et les employeurs et les employés les voient d'un bon œil<sup>341</sup>, bien qu'ils présentent certaines limites. Bender *et al.*<sup>342</sup>, par exemple, s'inquiètent du nombre de séances de traitement thérapeutique offertes aux clients des PAE, qui, d'après des données non scientifiques, aurait diminué considérablement et serait passé de sept à moins de trois par personne au cours des dix dernières années. Les auteurs concluaient qu'il est peu probable que l'on puisse résoudre efficacement des problèmes graves de toxicomanie ou de maladie mentale avec un aussi faible nombre de traitements thérapeutiques. Il faut s'attaquer à cette préoccupation particulière.

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<sup>340</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.5.1, p. 122.

<sup>341</sup> Neufeldt (2005).

<sup>342</sup> Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, section 6.5.1, p. 135.

Mary-Ann Baynton, directrice de l'Association canadienne pour la santé mentale en Ontario, a indiqué au Comité qu'il bon que les PAE prévoient le recours à des intervenants qui pourraient aider les personnes ayant une maladie mentale de bien des manières :

*Voilà qui m'amène à la dernière recommandation, c'est-à-dire le fait que nous devrions avoir des intervenants. Bien souvent, les employeurs disent qu'ils ont envoyé les formulaires, et que l'employé ne les a jamais remplis, ou n'a jamais rappelé, qu'il n'a pas fait ce qu'il avait à faire. Les employeurs ne comprennent pas que c'est souvent la maladie mentale qui fait en sorte qu'il est impossible pour cette personne de sortir du lit, encore moins de remplir un ensemble de formulaires compliqués. Nous examinons la possibilité de charger des intervenants de faire cela au nom des personnes aux prises avec des problèmes de santé mentale. Toutefois, c'est quelque chose que les PAE ou les employeurs pourraient offrir<sup>343</sup>.*

En ce qui concerne les PAE, le Comité recommande :

33

**Que les employeurs accroissent le nombre de séances de counselling offertes dans le cadre des Programmes d'aide aux employés (PAE), surtout là où l'accès à d'autres services de santé mentale est limité.**

**Que des recherches soient entreprises pour évaluer les PAE et que les résultats soient communiqués par le Centre d'échange des connaissances que le Comité recommande de créer dans le cadre de la Commission canadienne de la santé mentale (voir le Chapitre 16) en vue d'accroître l'efficacité de ces programmes.**

## 8.4 POSSIBILITÉS DE FORMATION

Les Canadiens souffrant de maladie mentale grave comptent beaucoup sur des programmes de réadaptation professionnelle pour lesquels il est difficile d'obtenir un financement suffisant. Le peu de recherches dont on dispose laisse entendre que toutes les approches en matière de réadaptation professionnelle n'affichent pas le même taux de succès pour ce qui est de permettre aux intéressés de trouver un emploi<sup>344,345,346</sup>.

<sup>343</sup> 5 juillet 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-f/soci-f/25ev-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

<sup>344</sup> J. Shankar et F. Collyer (2002), « Support needs of people with mental illness in vocational rehabilitation programs — the role of the social network ». *International Journal of Psychosocial Rehabilitation*, vol. 7, p. 15-28.

<sup>345</sup> A. F. Lehman (1995), « Vocational Rehabilitation in Schizophrenia ». *Schizophrenia Bulletin*, vol. 21, no 4, p. 645-656.

<sup>346</sup> J. Marrone et M. Gold (1995), « Employment Supports for People with Mental Illness ». *Psychiatric Services*, vol. 46, no 7, p. 707-711.

#### 8.4.1 Les programmes de réadaptation professionnelle

Les programmes de réadaptation professionnelle sont conçus pour aider les intéressés à devenir ou à demeurer économiquement indépendants grâce au travail. Entre autres programmes spécialisés, il convient de citer les programmes d'orientation professionnelle, d'évaluation du travail, d'adaptation au lieu de travail et de conditionnement, les emplois temporaires et les stages de transition.

**Les programmes de réadaptation professionnelle sont conçus pour aider les intéressés à devenir ou à demeurer économiquement indépendants grâce au travail.**

**L'expérience a montré qu'une réintégration rapide est plus efficace.**

La recherche portant sur la réadaptation professionnelle est de portée limitée et tend à être plus descriptive et anecdotique qu'autre chose. Le principe qui sous-tend la plupart de ces programmes est qu'une planification soigneuse combinée à une réintégration professionnelle lente et accompagnée augmentera les chances de succès. Or, l'expérience a montré qu'une réintégration rapide est plus efficace. Plus l'attente est longue, plus grands sont les risques de réduire l'employabilité, faute d'expérience de travail suffisante<sup>347</sup>.

Le fait que les personnes souffrant de maladie mentale soient reléguées à des postes subalternes et mal rémunérés où elles ont peu de chance de voir leur salaire progresser même lorsqu'elles conservent leur emploi aussi longtemps que leurs collègues sans handicap constitue une autre barrière à l'emploi. Le faible taux de réussite des programmes de réadaptation professionnelle tient aux attentes extrêmement basses du personnel, au protectionnisme paternaliste qui protège les intéressés de l'échec et de l'absence de responsabilisation<sup>348</sup>.

#### 8.4.2 Emploi assisté

Au milieu des années 1980 est apparue une nouvelle approche, appelée « emploi assisté ». Son objectif était d'éviter des modèles qui tendaient à encourager la dépendance et à réduire la nécessité pour les personnes ayant un handicap mental d'affronter la concurrence du marché de l'emploi. L'emploi assisté consiste à placer les clients aussi rapidement que possible dans des postes pour lesquels ils n'ont pas de préparation approfondie tout en leur fournissant un appui intensif et permanent sur place et une formation dispensée par des formateurs en milieu de travail.

**L'emploi assisté consiste à placer les clients aussi rapidement que possible dans des postes pour lesquels ils n'ont pas de préparation approfondie tout en leur fournissant un appui intensif et permanent sur place et une formation dispensée par des formateurs en milieu de travail.**

**Les modèles d'emploi assisté ont donné de meilleurs résultats que les services de réadaptation professionnelle traditionnels.**

D'après un examen comparatif des recherches sur le sujet, les modèles d'emploi assisté ont donné de meilleurs résultats que les services de réadaptation professionnelle traditionnels, les services de réadaptation professionnelle par courtage, les programmes de traitement de jour,

<sup>347</sup> J. Marrone et E. Golowka (1999), « If Work Makes People Sick, What do Unemployment, Poverty and Social Isolation Cause? » *Psychiatric Rehabilitation Journal*, vol. 23, no 2.

<sup>348</sup> *Ibid.*

les programmes de formation pré-professionnelle ou les ateliers protégés<sup>349</sup>. Après avoir analysé 18 essais contrôlés randomisés, les chercheurs ont établi que les participants à des programmes d'emploi assisté étaient beaucoup plus susceptibles d'être employés que les personnes qui reçoivent une formation pré-professionnelle (après 12 mois, 34 p. cent des personnes inscrites à un programme d'emploi assisté avaient trouvé un poste, contre seulement 12 p. cent pour celles qui avaient une formation pré-professionnelle)<sup>350</sup>. Il importe de noter toutefois que ce taux de réussite (34 p. cent) demeure relativement faible.

### 8.4.3 Initiatives de développement économique des consommateurs

Les initiatives de développement des consommateurs ont été créées dans les années 1990 par des personnes ayant une maladie mentale, déçues de l'échec des programmes de réadaptation professionnelle traditionnels visant à les aider à se trouver un emploi. Ces personnes ont commencé à mettre sur pied des entreprises dont elles étaient propriétaires. Le principe sous-jacent était que, si elles disposaient des outils nécessaires, elles pouvaient contribuer valablement à subvenir à leurs propres besoins et à faire valoir les avantages de services et de mesures d'aide en matière de santé mentale plus efficaces et plus responsables<sup>351</sup>.

Ces initiatives ont fait intervenir des organismes d'entraide dont des pairs-conseillers ont facilité les mesures de sensibilisation et d'aide mutuelle, ainsi que diverses entreprises, gérées par des personnes atteintes de maladie mentale, qui offraient des possibilités d'emploi et de perfectionnement en commerce. Les recherches menées sur ce type d'initiative montrent qu'il s'agit là d'un secteur prometteur pour ce qui est d'intégrer à la population active les personnes ayant une maladie mentale grave<sup>352</sup>.

**Les recherches menées sur ce type d'initiative montrent qu'il s'agit là d'un secteur prometteur pour ce qui est d'intégrer à la population active les personnes ayant une maladie mentale grave.**

#### 8.4.4 Le modèle du « club »

Dans bien des provinces et territoires, ce sont souvent des organismes apparentés à des clubs qui fournissent des services communautaires. Conçus dans les années 1940 par d'anciens malades psychiatriques, l'objet de ces clubs est de faciliter la transition entre l'hôpital et la collectivité<sup>353</sup>. Les clubs proposent des ateliers de perfectionnement professionnel, des groupes de résolution de problèmes, de la gestion de cas, des activités récréatives et des ateliers de préparation aux études<sup>354</sup>. Ils fonctionnent en vertu de règles égalitaires et sont gérés par le personnel et les patients qui cherchent à y instaurer un climat d'acceptation

<sup>349</sup> G. R. Bond, R. E. Drake, K. T. Mueser et D. R. Becker (1997), « Supported employment for people with severe mental illness: A review ». *Psychiatric Services*, vol. 48, no 3, p. 335-346.

<sup>350</sup> R. Crowther, M. Marshall, G. Bond et P. Huxley « Vocational rehabilitation for people with severe mental illness ». *The Cochrane Database of Systematic Reviews* 2001, numéro 2, no d'article : CD003080. DOI: 10.1002/14651858.CD003080.

<sup>351</sup> Initiative ontarienne de développement favorisant l'aide entre les pairs (octobre 2003), *The History of OPDI*. [http://www.opdi.org/about\\_us.html#history](http://www.opdi.org/about_us.html#history).

<sup>352</sup> K. Danley (1996), procès-verbal de la Conférence on Psychological Disabilities in the Workplace.

<sup>353</sup> The National Mental Health Consumers Self-Help Clearing House.

<sup>354</sup> C. McReynolds (2002), « Psychiatric Rehabilitation: The Need for a Specialized Approach ». *International Journal of Psychosocial Rehabilitation*, vol. 7, p. 61-69. [http://www.psychosocial.com/IJPR\\_7/approach.html](http://www.psychosocial.com/IJPR_7/approach.html).

sensible aux différences culturelles, où chacun peut socialiser, s'entraider et acquérir de l'expérience à la faveur d'emplois leur permettant de retourner progressivement à un emploi<sup>355</sup>.

Les programmes de formation pré-professionnelle sont conçus pour aider les personnes atteintes de maladie mentale à faire la transition vers un emploi grâce à un processus en deux étapes. La première consiste en l'établissement de journées pendant lesquelles les patients travaillent en équipe, avec le personnel, au bon fonctionnement et à la gestion du club. La seconde consiste à participer à des programmes d'emploi transitoire dans le cadre desquels les membres sont placés dans divers emplois temporaires rémunérés et contrôlés par le club. Malgré la longévité et la popularité de ces clubs, rares sont les signes qui prouvent qu'ils parviennent à atteindre leurs objectifs en matière de formation professionnelle.

#### 8.4.5 Ateliers protégés

Très populaires jusqu'à il y a dix ans environ, les ateliers protégés servent aujourd'hui essentiellement aux adultes accusant un retard de développement, bien que dans certaines provinces ils continuent de faire partie des programmes de réadaptation communautaire destinés aux personnes ayant une maladie mentale. D'après le peu de recherches menées sur le sujet, ce type d'atelier affiche un taux de succès faible (de l'ordre de 5 à 10 p. cent) pour ce qui est d'aider les personnes atteintes d'une maladie mentale à obtenir un emploi non protégé. En fait, la participation aux ateliers protégés pourrait bien ancrer chez les intéressés et dans la population en général des attentes très faibles quant à la capacité de travailler des personnes ayant une maladie mentale.

**Les ateliers protégés servent aujourd'hui essentiellement aux adultes accusant un retard de développement.**

#### 8.4.6 Initiatives fédérales

En 1997, pour répondre au rapport du Groupe de travail sur les personnes handicapées (rapport Scott) produit en 1996, le gouvernement du Canada a créé le Fonds d'intégration pour les personnes handicapées à titre de projet pilote. Ce fonds, administré par Développement social Canada, a obtenu un financement permanent en décembre 2000.

Le Fonds d'intégration est un programme de préparation à l'emploi des personnes ayant un handicap dont la participation à la vie active est faible ou nulle. Son objectif est d'aider ces personnes à se préparer à obtenir et à conserver un emploi ou à devenir travailleurs autonomes. Pour ce faire, le gouvernement collabore avec des organismes non gouvernementaux qui représentent les personnes handicapées, avec le secteur privé et avec les gouvernements provinciaux.

**Le Fonds d'intégration est un programme de préparation à l'emploi des personnes ayant un handicap dont la participation à la vie active est faible ou nulle. Son objectif est d'aider ces personnes à se préparer à obtenir et à conserver un emploi ou à devenir travailleurs autonomes.**

**L'un des atouts du Fonds d'intégration tient à son approche individualisée et souple en matière de prestation de services.**

<sup>355</sup> Clubhouse History. <http://www.telusplanet.net/public/club1/history.html>.

Le Fonds d'intégration appuie les mesures qui :

- encouragent les employeurs à embaucher des travailleurs handicapés;
- aident les personnes handicapées à se perfectionner, à réintégrer le marché du travail ou à devenir travailleurs autonomes;
- offrent des possibilités de travail pouvant mener à un emploi stable; et
- améliorent l'accès à l'emploi ou aux services d'emploi en fournissant une aide personnelle.

Le Fonds d'intégration vise aujourd'hui quelque 4 500 personnes handicapées par an, mais l'on ignore le pourcentage de celles de ces personnes qui ont une maladie mentale.

Selon une évaluation menée en 2001, l'un des atouts du Fonds d'intégration tient à son approche individualisée et souple en matière de prestation de services. À en juger par les évaluations des participants au Fonds et par les résultats, le programme les aide effectivement à trouver du travail et à améliorer leur employabilité et leur qualité de vie.

Le Comité recommande :

34	<p><b>Que le ministère des Ressources humaines et du Développement social, par l'entremise du Fonds d'intégration pour les personnes handicapées, facilite la mise en œuvre dans tout le pays d'un programme d'assistance en milieu de travail pour aider les personnes ayant une maladie mentale à se trouver un emploi et à le conserver.</b></p> <p><b>Que ce programme encourage la création d'entreprises dont les personnes souffrant de maladie mentale seront à la fois les exploitants et les propriétaires et appuie de telles entreprises.</b></p> <p><b>Que ministère des Ressources humaines et du Développement social signale le nombre de personnes ayant une maladie mentale auxquelles le Fonds d'intégration pour les personnes handicapées vient en aide.</b></p>
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## 8.5 ASSURANCE ET SOUTIEN DU REVENU

### 8.5.1 Commissions des accidents de travail<sup>356</sup>

Dans toutes les provinces et tous les territoires, les commissions des accidents de travail reçoivent de plus en plus de demandes de prestations pour des problèmes de santé mentale (« stress professionnel ») et, dans un nombre grandissant de cas, elles ont accordé les prestations.

L'Association des Commissions des accidents de travail du Canada a examiné les demandes de prestations pour stress professionnel présentées aux commissions, afin de découvrir combien de types de demandes étaient déposées tous les ans, s'il s'agissait de troubles épisodiques ou chroniques et quel était le montant des prestations versées dans chaque cas. Cet examen s'est avéré très difficile. Dans bien des cas, les commissions ne réunissent pas ce type de données ou, si elles le font, les données ne sont pas comparables parce que les définitions diffèrent (voir le tableau 8.1). Par conséquent, l'examen n'a pu fournir un tableau national du nombre de demandes de prestations pour stress professionnel ni des coûts des prestations connexes.

**Un important problème que soulèvent les prestations des commissions des accidents de travail est le fait qu'il est plus difficile de prouver la genèse d'un trouble mental que d'une maladie physique. Il n'est donc pas établi si et comment les troubles mentaux devraient être couverts dans un régime d'indemnisation des accidents du travail.**

Terry Bogyo, directeur de la Planification à la Workers' Compensation Board of B.C., a expliqué au Comité que les différences sur le plan du traitement des troubles liés au stress étaient la conséquence de cadres législatifs différents selon la province et le territoire.

*Il ne s'agit pas d'hésitation de la part des commissions, car les commissions ne font que ce que la loi leur dit de faire. Nous sommes la manifestation concrète de la loi. La loi nous régit tout comme la Loi sur l'indemnisation des agents de l'État, qui ne figurait pas sur cette liste, influe sur ce qui est couvert pour les employés fédéraux. Les différences découlent de la responsabilité qu'ont les législateurs de concevoir des lois qui reflètent les valeurs sociales, politiques, économiques, culturelles et historiques inhérentes à leur compétence. Il n'appartient pas à la commission de dire si cela est bien ou mal. Notre tâche est d'administrer la loi. Ce n'est pas une question d'hésitation. Si la loi dit que quelque chose est inclus, nous allons l'accepter<sup>357</sup>.*

Un important problème que soulèvent les prestations des commissions des accidents de travail est le fait qu'il est plus difficile de prouver la genèse d'un trouble mental que d'une

<sup>356</sup> Cette section est largement inspirée de : Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6, p. 127-129.

<sup>357</sup> 20 avril 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-f/soci-f/13eva-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

maladie physique. Il n'est donc pas établi si et comment les troubles mentaux devraient être couverts dans un régime d'indemnisation des accidents du travail. Dans un modèle de maladie professionnelle, l'indemnisation en cas d'invalidité dépend du fait que l'invalidité découle d'une exposition continue à des conditions dangereuses en cours d'emploi. Or, comme nous l'avons vu, la plupart des modèles étiologiques avancés des troubles mentaux incluent divers facteurs, tels que la vulnérabilité génétique, les circonstances du développement et des facteurs neurobiologiques, en plus de situations comme un cadre de travail stressant. La pondération relative de chacun de ces aspects n'est pas encore bien comprise, pas plus que les liens qui existent entre eux.

**TABLERAU 8.1**  
**COMMISSIONS DES ACCIDENTS DE TRAVAIL AU CANADA : COMPARAISON**  
**INTERPROVINCIALE DES PRESTATIONS POUR STRESS PROFESSIONNEL**

<b>Alberta</b>	<p>Les prestations pour stress professionnel sont accordées lorsque :</p> <ul style="list-style-type: none"> <li>▪ il y a un diagnostic confirmé conformément au Diagnostic and Statistical Manual of Mental Disorders de l'American Psychiatric Association;</li> <li>▪ les événements ou agents stressants reliés au travail constituent la cause principale de la maladie;</li> <li>▪ les événements reliés au travail sont excessifs ou inhabituels par rapport aux pressions normales que subit un travailleur moyen dans un poste semblable;</li> <li>▪ il y a une confirmation objective des événements.</li> </ul>
<b>Colombie-Britannique</b>	<p>Les formes de stress indemnissables comprennent :</p> <ul style="list-style-type: none"> <li>▪ le stress causé par un événement traumatique soudain et inattendu;</li> <li>▪ le stress qui découle d'un accident indemnissable, comme une grave anxiété après l'amputation d'une jambe.</li> <li>▪ Le stress provoqué par les pressions subies dans la vie personnelle et professionnelle quotidienne n'est pas indemnissable.</li> </ul>
<b>Manitoba</b>	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
<b>Nouveau-Brunswick</b>	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
<b>Terre-Neuve et Labrador</b>	La définition d'un accident au sens de la loi ne couvre le stress que lorsque ce dernier découle d'une réaction aiguë à un événement traumatique soudain et inattendu et exclut le stress découlant des problèmes de relations de travail.
<b>T.N.-O. et Nunavut</b>	Les demandes de prestations pour stress professionnel sont examinées au cas par cas.
<b>Nouvelle-Écosse</b>	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
<b>Ontario</b>	<p>Le stress mental est indemnissable lorsqu'il y a une réaction aiguë à un événement traumatique soudain et inattendu découlant de l'emploi et en cours d'emploi.</p> <p>Le stress mental découlant des décisions d'emploi de l'employeur ne donne pas droit aux prestations.</p>

Île-du-Prince-Édouard	La définition des accidents et des maladies professionnelles exclut le stress sauf lorsqu'il s'agit d'une réaction aiguë à une situation traumatique.
Québec	Le stress est indemnisable si le travailleur peut démontrer un lien entre la maladie et le travail ou un risque au travail.
Saskatchewan	Les prestations pour stress professionnel sont prévues expressément lorsqu'il est démontré clairement et de manière convaincante que le stress était excessif et inhabituel; les mesures courantes de relations de travail prises par l'employeur sont considérées normales et non inhabituelles.
Yukon	Le stress post-traumatique est admissible en vertu de la loi; la pratique actuelle consiste à évaluer au cas par cas tous les autres types de demandes de prestations reliées au stress.

Source : Paul Kishchuk, *Expansion of the Meaning of Disability*, étude commandée par la Yukon Workers' Compensation Board, mars 2003, p. 12.

Le Comité estime qu'il est important pour toutes les parties intéressées de s'attaquer à ces questions et il recommande :

35	<b>Que la Commission canadienne de la santé mentale (voir le Chapitre 16) travaille en étroite collaboration avec les gouvernements provinciaux et territoriaux ainsi qu'avec les commissions des accidents de travail, les employeurs et les syndicats du pays à l'élaboration de pratiques exemplaires concernant les prestations liées au stress d'ordre professionnel.</b>
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### 8.5.2 Les régimes d'assurance-invalidité des employeurs

Il existe deux types de régimes d'assurance-revenu en cas d'invalidité offerts par les employeurs, soit les régimes d'assurance-invalidité de courte durée (ICD) et les régimes d'assurance-invalidité de longue durée (ILD). Les régimes ICD remplacent un pourcentage (70 p. cent, p. ex.) du revenu d'emploi pré-invalidité pour des périodes inférieures à un an (p. ex., six mois).

Ils s'harmonisent généralement aux congés de maladie, à d'autres avantages sociaux et aux prestations d'assurance-emploi (AE), ce qui permet une continuité du revenu en cas de maladie ou de blessure invalidante.

**Pour motiver les prestataires à retourner travailler, les régimes d'assurance revenu sont conçus de façon à ce que le revenu de remplacement n'excède pas le revenu pré-invalidité.**

Les régimes ILD concernent des périodes d'invalidité prolongées. Les prestations sont habituellement versées après une longue absence, p. ex. six mois, et remplacent un pourcentage du revenu d'emploi pré-invalidité (p. ex. 70 p. cent). Elles sont habituellement versées pendant une période maximale de deux ans lorsque la personne est incapable d'exécuter les tâches de sa propre profession, ou plus longtemps, soit jusqu'à un âge maximal de 65 ans ou jusqu'au versement des prestations de retraite, si la personne est incapable

d'occuper un emploi raisonnablement comparable. Les prestations ILD versées par le régime de l'employeur peuvent être réduites d'un montant équivalent à celui que le prestataire reçoit du RPC-I (voir ci-après).

Les régimes ICD et ILD ont un important objectif en commun : ils encouragent les prestataires à reprendre le travail, de préférence leurs propres activités professionnelles ou, lorsque cela n'est pas possible, à occuper un autre type d'emploi. Ainsi, pour motiver les prestataires à retourner travailler, ils sont conçus de façon à ce que le revenu de remplacement n'excède pas le revenu pré-invalidité. Ce type d'assurance ne devrait pas décourager les intéressés de chercher un travail. Dans ce contexte, l'Association des psychiatres du Canada a expliqué que :

**Les employeurs, les gestionnaires et les assureurs doivent mieux connaître la maladie mentale et la toxicomanie afin de mieux gérer les prestations d'invalidité.**

Pour de nombreuses maladies, l'assurance-invalidité exige une définition précise de la maladie. Il est important que les patients psychiatriques invalides touchent un revenu suffisant pour se protéger contre de graves ennuis financiers pendant qu'ils ne peuvent pas travailler, mais il est tout aussi important de reconnaître que les prestations d'invalidité constituent un gain secondaire important qui empêche le progrès du patient et retarde son rétablissement. Il y a deux facteurs à prendre en considération : a) l'idée fausse mais répandue que le travail est nécessairement stressant et risque d'aggraver un trouble psychiatrique diagnostiqué; et b) la reconnaissance du fait que certains patients qui ont subi un trouble psychiatrique grave peuvent souhaiter éviter de s'exposer à ce qu'ils présument être des facteurs stressants au travail, parce qu'ils manquent de confiance malgré une amélioration clinique de leur état. Il faudrait reconnaître que retourner au travail le plus rapidement possible renforcera probablement l'estime de soi du patient, le ramènera dans un réseau social familial et contribuera à son rétablissement. Il a été démontré que la privation du travail peut être une cause de trouble psychiatrique<sup>358</sup>.

Les employeurs, les gestionnaires et les assureurs doivent mieux connaître la maladie mentale et la toxicomanie afin de mieux gérer les prestations d'invalidité. Dans une allocution récente, Bill Wilkerson, cofondateur et directeur général de la Global Business and Economic Roundtable on Addiction and Mental Health, déclarait :

Le secteur de l'assurance doit définir son point de vue à partir d'une connaissance des problèmes de santé mentale. Comme les entreprises en général, le secteur de l'assurance a besoin d'être sensibilisé à la santé mentale.

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<sup>358</sup> Association des psychiatres du Canada, « Insurability of the Psychiatrically Ill or Those With a Past History of Psychiatric Disorder » énoncé de position, 1988 [traduction].

C'est tout particulièrement vrai, par exemple, pour les aspects de la comorbidité de maladies mentales et de maladies physiques chroniques touchant à l'origine et à la durée de l'invalidité; à la complexité, à la durée et aux risques du traitement et du rétablissement; et au rythme et à la date du retour au travail.

Au niveau de la gestion des prestations, le secteur de l'assurance doit mieux connaître la santé mentale sur le plan médical[...] Il doit acquérir des connaissances sur l'univers grandissant des neurosciences et l'éclairage qu'elles peuvent apporter sur les origines du comportement. [traduction]

### 8.5.3 Programmes d'aide sociale provinciaux et territoriaux

Les programmes de soutien du revenu et d'assurance fournissent une certaine protection aux personnes atteintes de maladie mentale et incapables de travailler. Toutefois, les programmes gérés par les Commissions des accidents du travail et par le gouvernement du Canada (RPC(I) et AE) ont une caractéristique commune — pour se qualifier, les intéressés doivent avoir un emploi, et souvent depuis longtemps. Ceci dit, et compte tenu de la myriade d'autres critères d'admissibilité et des

**La rigueur des critères d'admissibilité, notamment l'obligation d'épuiser tout d'abord ses propres ressources financières, ne constitue pas le seul problème lié aux programmes d'aide sociale pour les personnes handicapées. Ces prestations, même si elles sont généralement plus généreuses que celles fournies en vertu des programmes d'aide sociale généraux, sont trop modestes pour éviter les difficultés financières.**

conditions temporelles dont s'assortissent les prestations, les personnes ayant une maladie mentale doivent souvent recourir aux programmes d'aide au revenu de dernier recours, en l'occurrence l'aide sociale (prestations de bien-être social) qu'offrent les provinces et les territoires.

Le plus souvent, les programmes d'aide sociale font une distinction entre les personnes capables de travailler mais incapables de trouver un emploi et celles incapables de travailler en raison d'une maladie, d'un handicap ou pour une autre raison. Par exemple, le gouvernement de l'Ontario offre le programme Ontario au travail aux personnes capables de travailler mais incapables de se trouver un emploi. Les candidats sont censés épuiser leurs propres ressources financières avant de pouvoir demander une aide. Le niveau des prestations est bas et les bénéficiaires sont tenus de participer à un programme de recyclage ou à d'« autres activités liées à l'emploi ». En bref, « les règles qui régissent l'admissibilité sont conçues de sorte que les personnes se tournent vers l'aide sociale seulement lorsqu'elles ont épuisé toutes autres ressources financières »<sup>359</sup>.

Par comparaison, ceux qui sont incapables de travailler peuvent se prévaloir du Programme ontarien du soutien aux personnes handicapées. Le niveau de ces prestations est environ la double de celui du programme Ontario au travail, et les bénéficiaires sont encouragés dans la

<sup>359</sup> Gouvernement de l'Ontario, ministère des Services sociaux et communautaires, « Qui est admissible au programme Ontario au travail? »  
<http://www.cfcs.gov.on.ca/CFCS/fr/programs/IES/OntarioWorks/FAQs/OW-q-eligibility.htm>.

mesure du possible à travailler; toutefois, la participation aux programmes connexes, comme le recyclage, est volontaire. De même, les candidats peuvent conserver une petite portion de leur actif personnel, soit 5 000 \$ en espèces et en REER<sup>360</sup>.

Malheureusement, comme c'est le cas avec les autres programmes d'aide au revenu, il est difficile d'être admissible au Programme ontarien de soutien aux personnes handicapées. Les candidats doivent avoir un handicap physique ou mental substantiel qui est continu ou récurrent et devant durer au moins une année. Étant donné la nature cyclique et imprévisible des maladies mentales, les personnes qui en souffrent et qui sont incapables de travailler peuvent ne pas avoir droit au programme. Elles n'ont donc d'autre choix que de participer au programme Ontario au travail, bien qu'elles ne soient pas ciblées par ce dernier.

La rigueur des critères d'admissibilité, notamment l'obligation d'épuiser tout d'abord ses propres ressources financières, ne constitue pas le seul problème lié aux programmes d'aide sociale pour les personnes handicapées. Ces prestations, même si elles sont généralement plus généreuses que celles fournies en vertu des programmes d'aide sociale généraux, sont trop modestes pour éviter les difficultés financières. Sont indiqués dans le tableau ci-après les montants d'aide et les exemptions (c.-à-d. les gains autorisés avant réduction des prestations) dans trois provinces :

**Ceux qui désirent réintégrer le marché du travail peuvent être découragés par des politiques dont l'effet est de réduire leurs prestations de portions variables de leur revenu gagné, ou de leur supprimer certaines prestations (remboursement des médicaments ou de soins médicaux) ou l'ensemble de leurs prestations.**

	Colombie-Britannique	Ontario	Québec
Montant mensuel pour une personne seule handicapée	856,42 \$ <sup>361</sup>	959,00 \$ <sup>362</sup>	835,67 \$ <sup>363</sup>
Gains exonérés	400,00 \$ <sup>364</sup>	160,00 \$ <sup>365</sup>	100,00 \$ <sup>366</sup>

<sup>360</sup> Gouvernement de l'Ontario, ministère des Services sociaux et communautaires, *Manuel du Programme ontarien de soutien aux personnes handicapées*.  
[http://www.cfcs.gov.on.ca/CFCS/fr/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP\\_handbook.htm](http://www.cfcs.gov.on.ca/CFCS/fr/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm).

<sup>361</sup> Gouvernement de Colombie-Britannique, Ministry of Employment and Income Assistance, *BC Employment and Assistance Rate Tables — Disability Assistance — À compter du 1<sup>er</sup> janvier 2005*.  
<http://www.eia.gov.bc.ca/mhr/da.htm>.

<sup>362</sup> Gouvernement de l'Ontario, Ministère des Services sociaux et communautaires, *Manuel du Programme ontarien de soutien aux personnes handicapées*.  
[http://www.cfcs.gov.on.ca/CFCS/fr/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP\\_handbook.htm](http://www.cfcs.gov.on.ca/CFCS/fr/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm).

<sup>363</sup> Gouvernement du Québec, Emploi et Solidarité sociale, *Prestations de base*.  
<http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base.asp>.

Ceux qui désirent réintégrer le marché du travail peuvent être découragés par des politiques dont l'effet est de réduire leurs prestations de portions variables de leur revenu gagné, ou de leur supprimer certaines prestations (remboursement des médicaments ou de soins médicaux) ou l'ensemble de leurs prestations.

Joan Edwards-Karmazyn, gestionnaire de la Consumers Health Awareness Network Newfoundland and Labrador (CHANNAL), a résumé le dilemme auquel les personnes atteintes de maladie mentale font face lorsqu'elles comptent sur les programmes d'aide sociale :

*Les membres de CHANNAL ont dit qu'il fallait davantage de logements abordables, réduire les obstacles qui limitent l'accès aux services d'éducation et de formation technique et augmenter les subventions salariales pendant la durée de versement de prestations de soutien du revenu.*

*Les membres ont dit qu'ils sont prisonniers du système s'ils veulent recevoir une indemnité pour les médicaments. Ainsi, ils hésitent à renoncer aux indemnités de revenu puisqu'il faudrait du même coup renoncer aux indemnités pour les médicaments. Les gens craignent de renoncer à leurs prestations parce que le revenu qu'ils pourraient gagner sur le marché du travail ne leur permettrait pas de se payer les 1 500 \$ par mois que coûtent leurs médicaments<sup>367</sup>.*

Par conséquent, le Comité recommande :

- |    |   |
|----|---|
| 36 | <b>Que le niveau des prestations versées dans le cadre des programmes d'aide sociale destinés aux personnes ayant une maladie mentale et les revenus que celles-ci sont autorisées à gagner sans pénalité soient relevés de manière à alléger le fardeau financier de ces personnes et les encourager à travailler.</b> |
|----|---|

<sup>364</sup> Gouvernement de la Colombie-Britannique, Ministry of Employment and Income Assistance, *Fact Sheet — Earnings Exemption for Persons With Disabilities*.

[http://www.eia.gov.bc.ca/factsheets/2004/PWD\\_EarningsExemption.htm](http://www.eia.gov.bc.ca/factsheets/2004/PWD_EarningsExemption.htm).

<sup>365</sup> Gouvernement de l'Ontario, ministère des Services sociaux et communautaires, *Manuel du Programme ontarien de soutien aux personnes handicapées*

[http://www.cfcs.gov.on.ca/CFCS/fr/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP\\_handbook.htm](http://www.cfcs.gov.on.ca/CFCS/fr/programs/IES/OntarioDisabilitySupportProgram/Publications/ODSP_handbook.htm).

<sup>366</sup> Gouvernement du Québec, Emploi et Solidarité sociale, *Prestations de base*.

<http://www.mess.gouv.qc.ca/securite-du-revenu/programmes-mesures/assistance-emploi/prestation-de-base.asp>.

<sup>367</sup> 14 juin 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-c.htm?Language=fr&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-e/soci-e/22eva-c.htm?Language=fr&Parl=38&Ses=1&comm_id=47).

Que les bénéficiaires d'aide supplémentaire, comme le remboursement partiel de médicaments, conservent cette aide pendant une période prolongée lorsque leur revenu augmente à un point tel qu'ils n'auraient plus droit à une aide au logement ou pour faire face à d'autres frais de subsistance.

#### 8.5.4 Les programmes fédéraux de sécurité du revenu<sup>368</sup>

Le gouvernement fédéral offre deux programmes de soutien du revenu qui peuvent aider les personnes ayant une maladie mentale : le programme de prestations d'invalidité du Régime de pensions du Canada et les prestations de maladie fournies dans le cadre de l'assurance-emploi. Un allègement fiscal est également offert sous forme de crédit d'impôt pour personnes handicapées.

##### 8.5.4.1 Les prestations d'invalidité du Régime de pensions du Canada (RPC-I)

Le volet invalidité du Régime de pensions du Canada (RPC-I) est le plus important programme de prestations d'invalidité au Canada. Ce programme est en général le « premier payeur » de prestations d'invalidité, devant d'autres entités comme les commissions des accidents de travail et les assureurs privés.

**Si on verse des prestations à une personne uniquement lorsqu'elle est totalement invalide, on fait preuve de discrimination, on la paralyse, on ne l'encourage pas à guérir.**

Les prestations de RPC-I sont versées aux participants de moins de 65 ans qui souffrent d'invalidité physique ou mentale « grave et prolongée » (durant au moins un an et empêchant d'occuper un emploi régulier) et qui répondent à certaines exigences particulières au sujet du niveau des revenus et des années de cotisation (des cotisations

**Étant donné que l'invalidité est actuellement synonyme d'inaptitude permanente au travail, les bénéficiaires du RPC-I hésitent à chercher ou à accepter un emploi, par crainte de perdre leurs prestations.**

doivent avoir été versées pendant quatre des six années antérieures). De 1980 à 2000, la proportion de bénéficiaires recevant des prestations du RPC-I attribuables à des troubles mentaux est passée de 11 p. cent à 23 p. cent. Les maladies mentales arrivaient au deuxième rang, derrière les maladies du système musculo-squelettique, et touchaient plus fortement les femmes que les hommes. En 2000, les troubles mentaux représentaient également la plus importante cause de prestations d'invalidité RPC-I chez les jeunes bénéficiaires.

**Un peu plus de la moitié des premières demandes au RPC-I sont rejetées.**

Depuis de nombreuses années, les personnes souffrant de maladie mentale et de toxicomanie et leurs représentants reprochent au RPC-I de ne pas correctement tenir compte du problème de la maladie mentale et de l'incapacité. En effet :

<sup>368</sup> Cette section est largement inspirée de : Comité sénatorial permanent des affaires sociales, des sciences et de la technologie (novembre 2004), Rapport 1 — *Santé mentale, maladie mentale et toxicomanie : Aperçu des politiques et des programmes au Canada*, chapitre 6.

- De nombreuses personnes atteintes de maladie mentale ont une expérience limitée sur le marché du travail. Parce que la maladie mentale frappe souvent au début de l'âge adulte, à un moment où les études ne sont pas achevées, les compétences professionnelles encore limitées et les carrières encore jeunes, un grand nombre de ces personnes ne sont pas admissibles au RPC-I parce qu'elles n'ont pas travaillé un nombre suffisant d'années. Par nécessité, beaucoup d'entre elles recourent aux programmes provinciaux d'aide sociale.
- Pour avoir droit aux prestations d'invalidité du RPC, le bénéficiaire doit accepter d'être désigné « inapte au travail à titre permanent », se déclarant ainsi tout à fait incapable d'occuper un emploi régulier. En raison de la nature cyclique et imprévisible des troubles mentaux, les personnes souffrant de maladie mentale peuvent travailler, mais souvent seulement à temps partiel; elles ne sont pas nécessairement capables d'assurer leur totale indépendance financière. À ce sujet, Jason Turcotte, du Bureau de l'Association canadienne de la santé mentale à Portage-la-Prairie, et membre de Partnership for Consumer Empowerment a déclaré au Comité : « On doit cesser de faire « tout ou rien ». Si on verse des prestations à une personne uniquement lorsqu'elle est totalement invalide, on fait preuve de discrimination, on la paralyse, on ne l'encourage pas à guérir<sup>369</sup> ». Les personnes souffrant de maladie mentale et de toxicomanie ont recommandé que le RPC-I prévoie des prestations partielles ou réduites au lieu de prestations intégrales, afin de leur permettre de travailler à temps partiel et de continuer de toucher une partie des prestations.
- Étant donné que l'invalidité est actuellement synonyme d'incapacité permanente au travail, les bénéficiaires du RPC-I hésitent à chercher ou à accepter un emploi, par crainte de perdre leurs prestations. Les personnes touchées sont pénalisées lorsqu'elles cherchent à améliorer leur situation, même si elles ne sont pas capables d'occuper un emploi régulier à plein temps.
- Un peu plus de la moitié des premières demandes au RPC-I sont rejetées pour cause d'inadmissibilité et près des deux tiers des personnes dont la première demande est rejetée ne demandent pas un réexamen du dossier. Il se pourrait que la proportion de demandes rejetées soit beaucoup plus élevée dans le cas des personnes souffrant d'une maladie mentale. Certains experts soutiennent que le système est conçu de manière à décourager les gens de demander des prestations auxquelles ils ont droit. C'est particulièrement le cas des personnes atteintes de troubles mentaux qui, en raison de leur maladie, ne sont peut-être pas en mesure de se battre contre le système.

**Une fois admissibles au RPC(I), les intéressés hésitent souvent à chercher le moindre travail ou à mener d'autres activités pouvant remettre en question leur état de santé officiel.**

<sup>369</sup> 31 mai 2005, [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-f/soci-f/16eva-f.htm?Language=f&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/Com-f/soci-f/16eva-f.htm?Language=f&Parl=38&Ses=1&comm_id=47).

Une fois admissibles au RPC(I), les intéressés hésitent souvent à chercher le moindrement à retourner sur le marché du travail ou à mener d'autres activités pouvant remettre en question leur état de santé officiel. Beaucoup craignent que, ce faisant, ils ne déclenchent une réévaluation de leur admissibilité au programme et perdent leur aide financière. Selon une personne atteinte de maladie mentale :

Le programme d'invalidité du RCP place les personnes dans une situation où elles doivent se dépeindre de la façon la plus négative qui soit dans le simple but de convaincre le travailleur social qu'elles ont besoin d'aide. Tout ce système est basé sur la pathologie et non pas sur le rétablissement<sup>370</sup>.

D'autre part, le RPC(I) pourrait avoir pour effet involontaire que les personnes atteintes de maladie mentale soient perçues comme inaptes à titre permanent. Les sociétés d'assurance privées exigent souvent de leurs clients qu'ils demandent d'abord des prestations de RPC(I) en raison du statut de premier payeur de ce régime, et ce afin de réduire leurs obligations financières. Toutefois, la personne qui se prévaut plutôt du RPC(I) que de l'assurance privée fournie par son employeur peut se distancer encore plus de ce dernier, ce qui pourrait rendre sa réintégration professionnelle encore plus difficile.

On a progressé ces dernières années sur un certain nombre de ces plans. Par exemple, les bénéficiaires du RPC(I) peuvent désormais gagner jusqu'à 4 100 \$ par an sans être privés des prestations. Les communications avec les demandeurs ont aussi été personnalisées, puisque l'on appelle ces derniers par téléphone pendant le processus de prise de décisions de manière à connaître leurs besoins particuliers et à les renseigner sur les programmes et les services.

En 2005, le RPC a également subi une modification d'ordre législatif, avec le rétablissement automatique des prestations de RPC(I). Ainsi, les bénéficiaires qui sont en mesure de recommencer à travailler peuvent le faire sans craindre de perdre leurs prestations. Si l'incapacité revient dans les deux ans qui suivent, ces personnes peuvent retrouver rapidement leurs prestations. Cecilia Muir, directrice générale, Bureau de la condition des personnes handicapées de Développement social Canada, a expliqué au Comité l'importance de ces modifications apportées au RPC(I) :

*Je reconnais que ce n'est pas la solution miracle, mais c'est déjà un grand progrès. Une période de cinq ans est maintenant prévue pendant laquelle on n'est pas tenu de présenter une nouvelle demande et de reprendre tout le processus. [...] D'après nos projections, au moins 300 personnes pourraient profiter de cette mesure chaque année<sup>371</sup>.*

Enfin, une stratégie de communication a été mise en place pour sensibiliser les personnes handicapées au fait que le RPC(I) les aide à retrouver un travail sans qu'elles ne risquent de

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<sup>370</sup> Association canadienne pour la santé mentale (27 novembre 2001), exposé de principe sur les programmes fédéraux de sécurité du revenu présenté au Sous-comité de la condition des personnes handicapées. <http://www.disabilitytax.ca/subs/cmha-f.pdf>.

<sup>371</sup> [http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13evb-f.htm?Language=F&Parl=38&Ses=1&comm\\_id=47](http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-f/soci-f/13evb-f.htm?Language=F&Parl=38&Ses=1&comm_id=47).

perdre leurs prestations. Les outils de communication comprennent un bulletin annuel intitulé « Maintenir le lien », un site Web et des lettres envoyées chaque année aux clients décrivant les dispositions de retour au travail prévues par le RPC(I). En outre, les clients les plus susceptibles de bénéficier du rétablissement automatique des prestations, surtout ceux ayant des incapacités épisodiques, reçoivent des lettres leur expliquant les nouvelles dispositions.

Dans son rapport de 2003, le Comité permanent du développement des ressources humaines et de la condition des personnes handicapées de la Chambre des communes reconnaissait que le RPC(I) ne répondait pas adéquatement à la question de la maladie mentale et de l'incapacité. Il a présenté un certain nombre de recommandations de manière à ce que ce programme tienne compte de la nature cyclique et imprévisible des maladies mentales. Il recommandait également au gouvernement fédéral d'élaborer, en consultation avec les divers intervenants et professionnels de la santé, des outils d'évaluation particuliers pour ces incapacités devant servir à évaluer l'admissibilité au RPC(I).

Dans sa réponse au rapport du Comité de la Chambre des communes, le gouvernement fédéral a indiqué que les lignes directrices établies pour le RPC(I) reconnaissaient déjà les incapacités récurrentes et épisodiques, notamment les troubles mentaux, et que bien des personnes ayant des troubles mentaux bénéficiaient déjà du programme. Il ajoutait :

Le gouvernement ne croit donc pas qu'il est nécessaire de modifier les règlements et les directives pour tenir compte des besoins des personnes atteintes de maladies épisodiques ou récurrentes. Puisque la détermination de l'invalidité aux fins du RPC se fonde sur les limitations fonctionnelles qui empêchent une personne de travailler et non seulement sur un diagnostic ou un pronostic médical, le processus d'évaluation peut prendre en compte les répercussions à court et à long termes des maladies récurrentes ou épisodiques sur l'habileté du client à fonctionner en milieu de travail<sup>372</sup>.

Le Comité rejette avec véhémence ce point de vue et recommande :

37	<b>Que les critères d'admissibilité au Régime de pensions du Canada-Invalidité (RPC-I) soient modifiés de manière à ce que les personnes souffrant de maladie mentale ne soient plus tenues de démontrer que leur maladie est grave et prolongée, mais seulement que leur maladie a été diagnostiquée, qu'elles sont inaptes au travail et qu'elles ont besoin d'un appui financier.</b>
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<sup>372</sup> Développement des Ressources humaines Canada. Réponse du gouvernement du Canada au rapport intitulé « À l'écoute des Canadiens : une première vision de l'avenir du Programme de prestations d'invalidité du Régime de pensions du Canada », p.24.

Que le gouvernement du Canada examine la façon dont il pourrait mieux coordonner les prestations de maladie versées dans le cadre de l'assurance-emploi (A-E) et les prestations versées dans le cadre du RPC-I et éliminer les obstacles structurels (notamment financiers) qui limitent les possibilités de réintégration professionnelle.

Que le gouvernement du Canada autorise le RPC à commanditer des recherches sur de nouvelles approches ciblant les personnes atteintes de maladies épisodiques, notamment d'ordre mental, et à faire des tests à ce sujet.

Que le gouvernement du Canada recherche des moyens d'encourager les employeurs à embaucher des personnes atteintes de maladie mentale, notamment en les exemptant des cotisations au RPC.<sup>373</sup>

#### **8.5.4.2 Assurance-emploi (AE)**

Les personnes atteintes de maladie mentale peuvent aussi avoir droit à des prestations d'AE comme source de revenu temporaire. Des préoccupations ont cependant été soulevées au sujet de l'AE :

- Les employés qui sont renvoyés pour « mauvaise conduite » ou qui démissionnent de leur emploi « sans motif valable » ne sont pas admissibles aux prestations d'AE. Par crainte de la stigmatisation, les personnes atteintes de maladie mentale cachent souvent leur maladie au travail. Quand elles éprouvent des difficultés au travail, elles peuvent être renvoyées ou démissionner sous l'influence de leur maladie, mais elles ne pourraient pas demander de prestations d'AE parce qu'elles n'ont pas déclaré leur maladie au préalable.
- Quand une personne demande des prestations de maladie dans le cadre de l'AE, elle doit obtenir un certificat médical indiquant la durée attendue de sa maladie. En raison de la nature imprévisible des maladies mentales, il est difficile de fournir ce genre de renseignements médicaux.
- Les personnes atteintes de maladie mentale ou de toxicomanie sont d'avis que l'AE ne devrait pas obliger les personnes atteintes de maladies ou d'invalidités récurrentes à travailler le nombre supplémentaire d'heures assurables exigé de ceux qui sont considérés comme des nouveaux venus sur le marché du travail. À leur avis, sans cette exonération, les personnes atteintes d'une maladie mentale sont désavantagées injustement. Peu sont en mesure de répondre aux critères d'admissibilité relatifs au nombre total d'heures assurables exigées des nouveaux travailleurs.

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<sup>373</sup> Les employeurs qui embauchent des personnes ayant une maladie mentale n'auraient pas à cotiser au RPC pour ces personnes pendant une période donnée.

Dans son mémoire au Comité, le D<sup>r</sup> Sunil V. Patel, à l'époque président de l'Association médicale canadienne, a recommandé que le gouvernement fédéral examine le RPC-I et les autres politiques fédérales de soutien du revenu afin de s'assurer que la maladie mentale se trouve sur le même pied que d'autres maladies et incapacités chroniques, pour ce qui est des prestations.

Le Comité est d'avis que les critères d'octroi des prestations de maladie au titre de l'assurance-emploi devraient être modifiés pour que quiconque est atteint d'une maladie mentale puisse s'en prévaloir plus facilement. Étant donné l'énormité du surplus du compte de l'assurance emploi<sup>374</sup>, ce changement ne représenterait pas un fardeau indu pour la population.

Le Comité recommande donc :

- |    |   |
|----|---|
| 38 | <b>Que l'on modifie les prestations de maladie versées dans le cadre de l'assurance-emploi, de manière à faciliter l'admissibilité des personnes souffrant de maladie mentale. Il faudrait notamment réduire, pour ces dernières, le nombre d'heures à travailler depuis la dernière demande.</b> |
|----|---|

#### ***8.5.4.3 Crédit d'impôt pour personnes handicapées***

Le crédit d'impôt pour personnes handicapées<sup>375</sup> est un crédit d'impôt non remboursable qui permet aux personnes handicapées de réduire les impôts qu'elles doivent payer. Ces personnes peuvent transférer ce crédit à leur conjoint ou à une autre personne qui les appuie. Le crédit vise à aider les personnes handicapées à assumer financièrement les coûts supplémentaires de la vie et du travail créés par leur incapacité. Le crédit de base s'élève à 1 037,76 \$ par an.

Il n'est pas facile d'obtenir le crédit d'impôt pour personnes handicapées. En effet, il faut avoir une déficience mentale ou physique grave et prolongée (d'un minimum d'un an) qui limite de façon marquée sa capacité d'effectuer une « activité courante de la vie quotidienne ». La définition d'une telle activité est très restrictive et ne comprend pas le travail, la tenue d'une maison, ni les activités récréatives ou sociales<sup>376</sup>. Par ailleurs, le montant de l'allègement fiscal est modeste. Le Comité recommande donc :

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<sup>374</sup> Dans son rapport de novembre 2004, chapitre 8, la vérificatrice générale faisait savoir que le surplus accumulé dans le compte de l'assurance-emploi s'élevait à 46 milliards de dollars. Voir : <http://www.oag-bvg.gc.ca/domino/rapports.nsf/html/20041108cf.html>

<sup>375</sup> Pour en savoir plus sur le crédit d'impôt pour personnes handicapées, voir : Agence du revenu du Canada, « Montant pour personnes handicapées ». <http://www.cra-arc.gc.ca/agency/ressourcekit/individuals/benefits-dtc-e.html>.

<sup>376</sup> Par « activités courantes de la vie quotidiennes » on entend le fait de percevoir, de penser et de se souvenir, de se nourrir, de s'habiller, de parler de façon à se faire comprendre par une personne de sa connaissance dans un endroit calme, d'écouter de façon à comprendre une personne de sa connaissance dans un endroit calme, d'éliminer (fonctions vésicales ou intestinales) et de marcher.

Que l'on modifie le critère d'admissibilité au crédit d'impôt pour personnes handicapées, pour faciliter l'admissibilité des personnes ayant une maladie mentale, et que l'on relève le montant de ce crédit.



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